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Adherence to an Oral Health Regimen among Head and Neck Cancer Patients: The Roles of Doctor-Patient Communication, Illness Perceptions, and Dispositional Coping

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Adherence to an Oral Health Regimen among Head and Neck Cancer Patients: The Roles of Doctor-Patient Communication, Illness Perceptions, and Dispositional Coping.

by

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This dissertation is dedicated to my amazing and wonderful husband, Luis Brandi, whose love and support has sustained me when nothing else could, and whose belief in me, when I didn't believe in myself, has kept me going when I thought I couldn't take another step. This is for you, with all my love always and forever, and a little bit longer.

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Adherence to an Oral Health Regimen among Head and Neck cancer Patients: The Roles of Doctor-Patient Communication, Illness Perceptions, and Dispositional Coping.

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Treatment of head and neck cancer with radiation therapy is associated with adverse side effects to the oral cavity and surrounding areas. These complications include mucositis, mucosal fibrosis and atrophy, salivary gland dysfunction, increased risk of dental caries, increased susceptibility to infections, tissue necrosis, taste dysfunction, and muscular and/or cutaneous fibrosis. The often permanent nature of the radiation-induced damage necessitates the maintenance of a strict oral care program, involving frequent flossing and brushing in addition to daily fluoride applications, for the rest of the patient's life. An additional concern among patients with head and neck cancer is the use of tobacco and alcohol. Both are known risk factors in the development of head and neck cancers and failure to abstain from either after diagnosis increases the risk for relapse and development of secondary cancers. The present study was a longitudinal investigation of several factors that may influence patients' consistency in following their prescribed oral care program and abstaining from alcohol and tobacco use, including, but not limited to,

patient satisfaction with the doctor-patient communication, patient coping, and patient illness perceptions. The study examined an integrative model seeking to explain patient adherence to the oral care regimen as well as tobacco and alcohol use. While results were inconclusive with respect to the model, there were several interesting findings, which were consistent with previous literature examining doctor-patient communication and illness perceptions among other cancer populations. Results from this study suggested that both satisfaction with doctor-patient communication and coping play an important role in forming patients' illness perceptions. Furthermore beliefs about the severity of oral complications emerged as a predictor of oral care at follow-up.

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OVERVIEW

Common to all of the head and neck cancers is the use of radiation therapy both as initial and adjuvant treatment. Besides the general side effects associated with radiotherapy, head and neck cancer patients being treated with radiotherapy often endure additional complications involving the oral cavity and surrounding areas (Dreizen, 1990). These complications arise from damage to fast growing cells in the mucosal tissue.

It is estimated that most patients with head and neck cancer who are being treated with radiation therapy will develop oral complications. As a consequence of these complications, patients with head and neck cancers who are being treated, or have been treated, with radiation therapy are required to follow a strict oral care regimen for the rest of their lives.

Further as both tobacco and alcohol use are know risk factors in the development of head and neck cancers, failure to restrict, or terminate, the use of both increases the risk for relapse and development of secondary cancers. This study is a longitudinal investigation of several factors that may influence patients' ability and consistency in following their prescribed oral care program.

The specific aims of the project were to:

1. Describe the pattern of adherence to a dental hygiene program and recommendations to restrict tobacco and alcohol use among head and neck cancer patients receiving radiation therapy.

2. Examine patients' perceptions of both the affective quality of the doctor-patient communication and the instrumental information provided during the consultation in relation to patient adherence, patients' illness perceptions, and patients' coping.
3. Examine the relationships between patients' coping, patients' illness perceptions, and patient adherence.
4. Examine the relationship between patients' illness perceptions and patient adherence.
5. Determine whether patients' coping moderate the relationship between patients' illness perceptions and patient adherence.
6. Determine whether patients' illness perceptions act as a mediator between patients' perceptions of doctor-patient communication and patient adherence.

The following chapters will provide a broad review of the epidemiology, biology, and treatment of cancer (chapter 1), discuss the concept of adherence and review predictors of adherence among cancer patients (chapter 2), discuss epidemiology and treatment of head and neck cancer specifically, present the current study (chapter 3), and describe the methods of the present study (chapter 4). Chapter 5 presents the findings of the study, and Chapter 6 provides a discussion of the results in the context of previous research.

CHAPTER 1: LITERATURE REVIEW

The aim of this chapter is to provide information about cancer and cancer treatment in order to better understand the context within which cancer patients find themselves. The chapter provides a general overview of the epidemiology, biology, and treatment of cancer. The first section, cancer as a public health concern, discusses the epidemiology of cancer, the cost to society of cancer, and cancer prevention efforts. The second portion of the chapter presents a brief overview of the development and biology of cancer, and common risk factors. Finally, the chapter provides an overview of the most common cancer treatment modalities, and the importance of cancer treatment adherence in relation to clinical outcomes.

Cancer as a Public Health Concern

Cancer is the second leading cause of death in the U.S. Recent advances in medical technology have significantly reduced mortality rates; however, approximately 533,000 people still die from cancer each year (Cancer Prevention & Early Detection, 2003). Moreover, cancer incidence rates continue to rise with an estimated 1.2 million new cases diagnosed each year (Ries et al., 2003; Cancer Prevention & Early Detection, 2003). The life time prevalence of cancer is about 33% for women and 50% for men and currently 8.9 million Americans have a history of cancer (Cancer Prevention & Early Detection, 2003).

These numbers are alarming considering that a number of environmental risk factors such as smoking, exposure to ultraviolet light, poor diet, alcohol use, exposure to certain chemicals (Cancer Prevention & Early Detection, 2003), and the contraction of viruses

such as HIV, HPV, Cytomegalovirus, and the hepatitis B virus can be reduced if not all together eliminated. Not only does cancer take a huge toll in terms of human lives, the illnesses that fall within this category are also vastly expensive for society (Greenwald, 2002). According to estimates the overall financial cost of cancer is $150 billion a year. This number includes $50 billion a year spent on direct medical costs, $10 billion in lost worker productively due to cancer and $75 billion due to premature death.

Research on cancer has covered both the treatment and prevention of cancer. Advances in medical research and technology have been highly successful and despite the increase in incident rates over the last 20 years, survival rates have improved from 50% in 1973 to 62% in 1998 (Greenwald, 2002). Two other key elements in the fight against cancer are the focus on prevention through the reduction of risk factors and the promotion of early diagnosis through regular screening of high risk populations (Greenwald, 2002). The sedentary lifestyle adapted by many inhabitants of western society, along with poor dietary choices and other maladaptive health behaviors, such as smoking, are among the most common risk factors for cancer (Cohen & Baum, 2001; Baum & Posluszny,1999) and primary interventions have been focused on educating the public at large about these (Robertson, Bound, & Segal, 1998; Greenwald, 2002). In addition, the implementation of regular screening procedures such mammograms for women, prostate exams for men, and colonoscopies for both sexes, have significantly increased the proportion of cancers that are diagnosed in the early stages (Baum & Posluszny, 1999). However, early detection through cancer screening is only effective when recommended screening schedules are adhered to. Despite efforts on the public health level, an increasing number of people are living with cancer and within the last two decades more and more research

has focused on the psychosocial aspects of being diagnosed with cancer, treated for cancer, living with cancer, and surviving cancer.

The broad diagnosis of cancer encompasses many different illnesses; however, for the purpose of this study a general description of the illness and its treatment is discussed to better understand the context within which the cancer patients must cope.

Cancer Facts

Biology of Cancer

The term *cancer* covers a broad category of illnesses characterized by the presence of one or more neoplastic growths. A neoplasm is a cell, or group of cells, which have lost the mechanism that normally controls the cell cycle and consequently grow at an abnormally increased rate, often invading surrounding tissues and organs (Duckett & Belldegrun, 1992). The first step during which a cell is primed, through the exposure to carcinogens, to become cancerous is known as the initiation phase. Once primed, the cell's DNA changes and the cell is considered cancerous. This phase is known as promotion. The change in DNA is what causes the uncontrolled growth, or dividing, of the cell, which ultimately results in a tumor (Stockhorst, Klosterhalfen, & Steingrueber, 1998; Duckett & Belldegrun, 1992).

Not all tumors are malignant. There are two main differences between benign and malignant tumors (Duckett & Belldegrun, 1992). First, malignant tumors have no clearly defined borders and directly invade surrounding tissue, whereas benign tumors are clearly defined and do not spread to surrounding tissue. Second, malignant tumors have the ability to spread throughout the body by shedding malignant cells that travel through

blood and lymph vessels to other tissues where they establish new growths, whereas benign tumors do not (Dollinger, Rosenbaum, & Cable, 1997). This shedding of cells is what is known as metastasis. As a general rule, malignant tumors are what we are concerned about when we talk about cancer. There are a few exceptions to this rule involving benign tumors that, either because of their size or location, are causing functional impairment necessitating treatment. The stage of cancer is classified by the TNM System which indexes 4 stages of severity, reflecting tumor size (T), degree of spread to lymph nodes (N), and metastasis (M) (Fleming et al, 1997).

Normally, the immune system, which is the body's natural defense against cancerous cells, is proficient in detecting and eliminating cancer cells before they can replicate (Duckett & Belldegrun, 1992). One of the most important features of the immune system is its ability to recognize foreign cells or tissue (Naftzger & Houghton, 1991; Bancroft B., 1994). All of the cells in our body carry what is known as a "self-marker," however, microorganisms such as virus and bacteria lack this marker and can thus be labeled as foreign to the host (Bancroft B., 1994). Once a cell has been recognized as foreign it is either killed immediately (Natural Killer Cells) or tagged for later destruction (Macrophages) (Bancroft B., 1994). White blood cells, such as macrophages and natural killer cells, are the first line of response (Bancroft B., 1994). These cells circulate throughout the body constantly and, when they come across a foreign cell alert the rest of the immune system to the presence of foreign cells in two ways (Naftzger & Houghton, 1991; Bancroft B., 1994). First, they produce and release small proteins known as *cytokines*, which stimulates other cells collectively known as lymphocytes. Lymphocytes fall into two broad categories: B cells, which produce antibodies (proteins that attach

themselves to the markers of foreign cells), and T cells, which serve two functions. T cells produce and release cytokines that stimulate the growth and activation of: (1) B cells and (2) a subset of T cells known as cytotoxic T cells, which can destroy foreign cells on direct contact (Pardoll & Topalian, 1998). The immune system is able to kill a majority of cancerous cells because these cells, as a result of their altered DNA display markers, which label them as foreign to the host (Duckett & Belldegrun, 1992; Post-White, 1996). However, for any given cell to elicit an immune response the marker displayed must be sufficiently different from the self-marker (Duckett & Belldegrun, 1992; Naftzger, 1991). Cancer often develops when the markers of a cancerous cell do not elicit an immune response (Post-White, 1996; Naftzger, 1991). Further, any condition that weakens the immune system, such as HIV+ status, AIDS, autoimmune diseases, and immunosuppressive medications, make the host more susceptible to developing cancer. Ironically, the most common forms of cancer treatment, such as radiation therapy and chemotherapy, adversely affect the immune system; the very system that normally defends against cancerous growths.

Risk Factors for Cancer

Factors disrupting the mechanism controlling normal cell growth are known as carcinogens. Some common carcinogens are chemicals, such as those found in tobacco smoke and alcohol, radiation (e.g. sunlight), poor diet (high in fat and low in fiber), and viruses such as HIV, HPV, Cytomegalovirus, and the hepatitis B virus all of which can cause cancer (Meng, Maskarinec, Lee, & Kolonel, 1999, Cancer Prevention & Early Detection, 2001). Carcinogens often play a role in the initiation phase by either

promoting mutations in the cell's normal cycle or by reducing the immune system's ability to recognize and eliminate cancerous cell. However, carcinogens are typically not sufficient in causing cancer (Schull, 1991). Most cancerous growths result from a combination of the introduction of a carcinogen and inherent genetic flaws (known as promoters) within the cell, which makes the cell more susceptible to becoming cancerous (Tomatis, 1998). Genetic risk factors encompass having a family history of cancer or chromosomal abnormalities, such as Down's syndrome (Schull, 1991).

Once the diagnosis of cancer has been given, treatment is usually prompt and aggressive. The following section will discuss the different cancer treatments in more detail along with adherence rates to each treatment.

Cancer Treatment

Cancers that are in the early stages can be treated very successfully (van Dongen & Snow, 1997), and one of the key predictive factors of successful treatment is early diagnosis. However, early detection of cancer is often difficult. For example, a tumor is usually not detectable until it has divided into 1 billion cells, or gone through 30 doublings, and most people do not experience any symptoms of illness prior to this point (Naftzger, 1991). The time between promotion and detectable size is known as the "silent" period and can last from many months to several years, thus, further complicating early detection of malignant tumors (Dollinger, Rosenbaum, & Cable, 1997; Naftzger, 1991).

The four most common treatment modalities for cancer are surgery, chemotherapy, radiation, and immunotherapy. All of these treatments have been proven highly successful in treating cancer depending on stage, site, and metastasis.

Surgery

Surgery is the oldest form of cancer treatment and involves the surgical removal of tumors (Mocellin, Rossi, Lise, and Marincola, 2002). Two factors determine the appropriateness of surgery as a treatment option. One factor is the degree to which the cancer has spread (Lenhard, Osteen, & Gansler, 2001). Tumors that are localized and have not spread are usually good candidates for surgical removal, whereas tumors that have metastasized often complicate surgery or make surgical removal of several tumors inappropriate. The other factor, which must be considered when evaluating surgery as a treatment option, is the question of whether tumors can be removed without damage to vital organs such as the liver or the brain (Lenhard, Osteen, & Gansler, 2001; Mocellin, Rossi, Lise, and Marincola, 2002).

Surgery is often used in combination with other treatment modalities such as chemotherapy and radiation therapy (Pazdur, Coia, Hoskins, & Wagman, 1996). Either of these may be given *prior* to surgery to shrink tumors and, thus, simplify the surgical procedure. This is known as neoadjuvant therapy. Adjuvant therapy, treatment with either chemo or radiation *after* surgery, is given to insure that tumor cells that are too small to be visible or tumor cells that could not be removed through surgery do not cause later recurrence (Dollinger, Rosenbaum, & Cable, 1997). For head and neck cancer patients the side effects of surgery not only involve the general concerns of recovery and

pain management, they often have to cope with permanent disfigurement of the face and neck, that can not be hidden by clothing (Hagedoorn & Molleman, 2006; Pruzinsky, Levine, & Persing, 2006). In addition, there is always a risk involved when undergoing general anesthesia and having surgery that involves vital organs and/or their surrounding tissue.

Chemotherapy

Chemotherapy is the use of chemical agents to destroy cancer cells. While there are many different anticancer drugs, most agents used in chemotherapy kill cancer cells by affecting their DNA synthesis or metabolic processes (Stockhorst, Klosterhalfen, & Steingrueber, 1998). Chemotherapy is in particular appropriate for cancers that have metastasized, or leukemias, as the drugs act on a systemic level (Burke, Wilkes, Ingwersen, Bean, & Berg, 1996). The flip side of this important property is coincidently one of the main problems in the use of chemotherapy as these agents not only affect cancer cells but also normal healthy cells. The balance between a therapeutic dose and a toxic dose is a delicate matter (Dollinger, Rosenbaum, & Cable, 1997) and many of the common side effects of chemotherapy are a direct consequence of the toxicity of these drugs to normal cells (Camp-Sorrell, 1997).

Chemotherapy is most commonly administrated by mouth, through a vein, or into muscle tissue (Burke, Wilkes, Ingwersen, Bean, & Berg, 1996). Recently, however, new methods have been applied to increase the local concentration of chemotherapy at the tumor site itself leading, not only, to more efficient treatment, but also a reduction in some of the systemic side effects (Jurcic & Scheinberg, 1994). Such methods include

administration directly into a specific cavity, the abdomen, the lung, the central nervous system, or application directly onto the skin (Jurcic & Scheinberg, 1994). Another complication of treatment with chemotherapy is the length and intensity of treatment. While there is great variation in treatment regimens due to type of cancer and individual response rates, chemotherapy is generally spaced out over an extended period of time with the average treatment regimen lasting anywhere from to 4 to 12 months (Burke, Wilkes, Ingwersen, Bean, & Berg, 1996). Within this time period treatments are usually given on a daily, or weekly, schedule with recovery periods interspersed between treatments and most patients receive their chemotherapy every 3 to 4 weeks.

Chemotherapy is known for its adverse side effects. As previously mentioned chemotherapy not only destroys cancerous cells but also affects healthy cells. The healthy cells that are most at risk for being destroyed by chemotherapy are those which tend to grow at a fast rate, particularly blood cells (Camp-Sorrell, 1997). There are three types of blood cells and each type has a special function. Red blood cells carry oxygen to all of the cells in the body, white blood cells are part of the immune response and are important in preventing and fighting off infections, and platelets play a central role in stopping bleeding.

Chemotherapy can cause a reduction in the red blood cell count leading to anemia (Camp-Sorrell, 1997). Common symptoms of anemia include: fatigue, dizziness, headache, shortness of breath or difficulty breathing, chest pain or palpitations, irritability, ringing in the ears, and feeling chilled.

Another adverse effect of chemotherapy is the reduction of white blood cell counts, a condition known as neutropenia (Stockhorst, Klosterhalfen, & Steingrueber, 1998).

Patients with neutropenia are at increased risk for opportunistic infections and may also have a difficult time recovering from infections. Signs of neutropenia include: fever, coughing, excess mucous, shortness of breath or painful breathing, soreness or swelling of the oral cavity, mouth ulcers and fungal infections, pain or burning with urination, diarrhea, redness, pain or swelling of the skin, pus or drainage from any open cut or sore, and an overall feeling of being sick in the absence of fever or any other sign of an infection (Camp-Sorrell, 1997).

Chemotherapy is also associated with low platelet counts, a condition known as thrombocytopenia (Camp-Sorrell, 1997). Platelets play an important role in clotting blood, and patients with thrombocytopenia are at increased risk of bleeding from minor injuries, such as a small cut or bump. Common symptoms of thrombocytopenia include: excessive bruising of the skin, petechiae (tiny red spots on the skin), bleeding gums, frequent nosebleeds that are difficult to stop, excessive bleeding from a small cut, and blood in the urine and stool.

Other fast growing cells include hair cells and cells of the intestinal lining and mucous membranes. The consequence of chemotherapy on these cells, lead to some of side effects most commonly associated with chemotherapy such as constipation, diarrhea, hair loss, mouth sores, and nausea and vomiting (Cull, 1990; Stockhorst, Klosterhalfen, & Steingrueber, 1998).

Other studies have cited psychological and cognitive impairments as direct consequences of chemotherapy stressing the importance of psychological and/or psychiatric consultations with patients receiving chemotherapy (Silberfarb, Philibert, & Levine, 1980; Cull, 1990).

Radiation Therapy

Radiation is another form of cancer treatment and involves exposing tumors to high-energy x-rays. Similarly to chemotherapy, radiation destroys cells by damaging the cells' DNA and preventing them from replicating (Coia, 1998). Radiation is widely used to treat many different types of cancer, sometimes as a primary treatment modality and, at other times, in combination with surgery and/or chemotherapy. Radiation is particularly lethal for cells that are in the growing and dividing phase of the cell cycle. Because, cancer cells grow and multiply at a much higher rate than most normal cells, radiation therapy is an effective treatment for cancer. However, as with chemotherapy, normal cells are also affected, particularly those that grows fast such as hair cells, cells lining the intestines, and blood cells.

Radiation can be administered externally (most common) or internally (less common) (Coia, 1998). During external radiation high-energy x-rays are directed to the particular area of the body where the tumor resides (Coia, 1998). In most cases treatments are given once a day, Monday through Friday on an outpatient basis, over a period of 3 to 7 weeks. During internal radiation treatment the radioactive substance is sealed and held in place at site of the tumor by mechanical devices, swallowed by mouth, or injected into the body (Coia, 1998). During treatment with internal radiation most patients are hospitalized for 3-7 days as they can be considered a radioactive source and necessary precautions must be taken. Side effects are generally limited to the region of the body being treated. Some of the most common side effects of radiation are skin irritation, hair loss, discomfort swallowing, nausea, altered taste, diarrhea, and fatigue (National Cancer Institute, 2002; Miaskowski & Lee, 1999).

Immunotherapy

The most recent development in cancer treatment is the use of biological response modifiers (BRMs) also known as immunotherapy (Greenwald, 2002; Salgaller, 2000; Mocellin, Rossi, Lise, & Marincola, 2002). BRMs are used to help the patient fight cancer by strengthening their immune response to cancer cells (Bremers & Parmiani, 2000). The functions of BRMs fall into three major categories. The first group consists of agents that help boost the body's normal immune response to cancerous cells, the second group is comprised of agents that directly affect the tumor, and the third group includes agents that reduce a tumor's ability to metastasize and differentiate. Common agents currently used in immunotherapy are interferons (INFs), interleukins (IL-), colony-stimulating factors (CSFs), and monoclonal antibodies (MoAbs). The use of T cells and tumor necrosis factors (TNFs) are still being investigated (Salgaller, 2000; Pardoll & Topalian, 1998). Both interferons and interleukins belong to the broader category of cytokines which are proteins produced by cells of the immune system that regulate the activity of B and T cells (Grimm, 2000; Mocellin, Panelli, Wang, Rossi, & Marincola, 2002; Kintzel & Calis, 1991).

Interleukin-2 is an immunomodulating agent that stimulates the proliferation, activation, and differentiation of important cells of the immune system such as T and B cells and natural killer cells (Kintzel & Calis, 1991; Mocellin, Panelli, Wang, Rossi, & Marincola, 2002). Most clinical studies of interleukin-2 has involved the treatment of patients with renal cell carcinoma, melanoma, and colorectal cancer who historically respond poorly to conventional therapy (Kintzel & Calis, 1991). Results have indicated a positive response to therapy with interleukin-2 among these patient (Kintzel & Calis,

1991) and suggested that the administration of interleukin-2 (IL-2) to patients with cancer may mediate the regression of established cancers (Mocellin, Panelli, Wang, Rossi, & Marincola, 2002)

Colony-Stimulating factors are growth factors, which mediate the proliferation, maturation, regulation, and activation of red and white blood cells as well as platelets (Salgaller, 2000). As discussed previously, one of the major side effects of chemotherapy is the destruction of blood cells. The ability to stimulate the growth of these cells provides an opportunity to treat tumors more aggressively with higher doses of chemotherapy that under normal circumstances would be highly toxic to the patient.

A recent development in immunotherapy involves the use of monoclonal antibodies (MoAbs) (Jurcic & Scheinberg, 1994). In this form of therapy samples of the patient's tumor cells are taken and processed to reveal specific antibodies to the tumor-associated antigens. Such antibodies are then developed in a lab and injected back into the patient where, it is hoped, they will seek out and attach themselves to the tumor cells (Salgaller, 2000). Research in this area is also examining the use of monoclonal antibodies as carriers of other therapeutic agents such as chemotherapy or radioactive substances that can, by way of the tumor specific antibodies, be delivered directly to the tumor (Bast, Zalutsky, Kreitzman, Sausville, & Frankel, 2000). This approach would be more effective and significantly less toxic than the conventional treatment modalities currently available. (Greenwald, 2002; Jurcic & Scheinberg, 1994).

Most treatment with BRMs is delivered though IV or injections. Potential side effects are numerous. Some are life threatening (see below), and require that the administration of both IL-2 and MoAbs are carried out on an in-patient basis (Bast, Zalutsky, Kreitzman,

Sausville, & Frankel, 2000; Kintzel & Calis, 1991). Treatment with INF is commonly associated with fever, chills, tachycardia, muscle aches, malaise, fatigue, headaches, decreased white blood cell count, anemia (with prolonged therapy), decreased platelets, hair loss, loss of appetite, nausea, vomiting, and diarrhea. In addition are central nervous system toxicities, ranging from mild confusion and sleepiness to serious seizures. Acute kidney failure is rare, but can occur. Side effects of IL-2 treatment include hypotension, ascites (the accumulation of fluid in the abdominal cavity), generalized body edema, pulmonary edema, chills and fever, headache, malaise, nausea, vomiting, loss of appetite, diarrhea, mucositis, liver dysfunction, in addition to CNS effects such as lethargy, confusion, disorientation, hallucinations, anxiety, and sometimes depression (Walker, Walker, Heys, Lolley, Wesnes, & Eremin, 1997; Smith and Khayat, 1992; Pavol, Meyers, Rexer, Valentine et al, 1995).

Monoclonal antibody therapy has been associated with side effects such as dyspnea (difficulty breathing) and mild wheezing, fever, chills, headache, rash, nausea, vomiting, tachycardia, and serious allergic reactions. In contrast, side effects of treatment with CSF are usually benign (Salgaller, 2000).

Complimentary Measures

Cancer prevention health behaviors such as eating a low fat, high fiber diet, regular exercise, low alcohol consumption, and abstaining from tobacco use are also recommended for cancer patients (Cohen & Baum, 2001) for three reasons. First, poor health behaviors such as a high fat, low fiber diet, sedentary life style, alcohol use, along with use of any form of tobacco have all been found to be risk factors in the development

of cancer (American Cancer Society, 2002; Baum & Posluszny, 1999) and thus continue to present a threat to cancer patients. Second, continued use of alcohol and tobacco may reduce the effectiveness of cancer treatments (Des Rochers, Dische, & Sounders, 1992; Browman, Wong, Hodson, et al, 1993). Third, as reviewed above, side effects of cancer treatments include fatigue, treatment induced food aversion, and anorexia which can be relieved by moderate exercise and proper nutrition.

In summary, the three most common and effective treatments of cancer are surgery, chemotherapy, and radiation therapy. The use of biological Response Modifiers in cancer treatment is still being investigate, but research has showed promising results and some potential benefits over chemotherapy and radiation therapy as the allow delivery of both treatment modalities at a cellular level, thereby reducing adverse side effects. Complimentary measures are another important aspect of cancer treatment. They support overall health of the patients allowing for more aggressive treatment, and may prevent relapse or secondary cancers upon the conclusion of treatment.

Cancer Treatment Outcomes

As mentioned earlier, new medical technology has significant improved cancer survival rates. Part of this improvement can be attributed to technology that has made early diagnosis possible, but much of the increase in survival rates can be directly attributed to advances in treatment options. This section will provide a brief presentation illustrating the effectiveness of cancer treatments.

Chemotherapy

When appropriately administered chemotherapy has been found to be a highly effective treatment for cancer (Green & Hortobagyi, 2002). In a study of women being treated with chemotherapy for breast cancer (Bonadonna & Valagussa, 1981) results revealed a clear dose-dependent effect, indicating that the effectiveness of chemotherapy increased among patients who received the full or nearly full dose (greater than or equal to 85 per cent of the planned dose). Specifically, patients who received all 12 cycles of chemotherapy in addition to radical mastectomy had a five-year relapse-free survival of 77%. In contrast, among patients who received less than 65% of the planned dose the five-year relapse-free rate of survival was 48%, which is similar to the five-year relapse-free survival among patients treated only with radical mastectomy, which was found to be 45%.

Similarly, three other studies of cancer patients found that when IV doses of chemotherapy received by the patient were less than the standard recommendation, disease outcome was negatively compromised (Tannock et al, 1988; Wood et al, 1994). The importance of providing the optimal dose and number of treatments with chemotherapy has also been demonstrated in studies of children with leukemia (Eden, Stiller, & Gerrard, 1988; Bonadonna, Gasparini, & Rossi, 1980). Here results showed that receiving the standard recommendations of dose and number of treatments was associated with prolonged survival. Finally, preliminary results have suggested that while the link between neoadjuvant chemotherapy and survival rates remains unclear, neoadjuvant therapy has been shown to reduce the need for surgical intervention (Green & Hortobagyi, 2002).

Radiation Therapy

Consistent results have been found for radiation therapy. In a retrospective analysis of survival rates among patients treated with radiotherapy for head and neck cancers Cathcart, Dunican, and Halpern (1997) the outcomes and treatments of 69 patients were analyzed. Patients who completed less than 80% of the prescribed treatment were categorized as non adherent. The overall five year survival of patients who completed treatment was 38% versus 12% for patients who failed to complete treatment and the mean survival time for the compliant group was 24.2 months versus 12.6 months for the noncompliant group. Authors concluded that the length of patient survival from head and neck cancer is directly related to compliance to radiation treatment.

Compliance appears to be directly related to better overall survival and mean survival time. These results are supported by another study of women undergoing radiation therapy for early stage breast cancer (Li, Brown, Ampil, Burton, Yu, & McDonald, 2000). In this study full compliance was defined as completion of the entire course of radiation therapy and clinical follow-up. The authors reported that among patients who failed to complete the entire radiation regimen, 53% did not improve with treatment, whereas only 5% of patients who completed their radiotherapy failed to show improvement. Another study examining the role of radiation scheduled in overall survival (Alden, O'Reilly, Topham, Lowry, Brodovsky, & Curran, 1996) concluded that the number of days between radiation therapy treatments was highly predictive of overall survival. In other words delay or disruption of treatment had a negative impact on survival rates. Specifically, results showed that among patients who received treatments less than 55

days apart survival rates were significantly higher (56%) than survival rates among patients whose treatments were more than 66 days apart (15%).

Immonotherapy

On the other hand, treatment outcomes of immunotherapy vary depending on specific agents and form of cancer. Given the recent development in this field, BRMs are still undergoing clinical trials. However, preliminary research has produced optimistic results. The use of interferons in cancer treatment has been found to have response rates from 15-90% depending on cancer type. The mechanism by which interferons work in yet unclear, but it is believed that they may make tumors appear even more foreign and thus increase the likelihood of attack by antibodies and other immune cells. The only FDA approved use of interferons in cancer therapy is the use of INF-α2b (McMasters & Swetter, 2003). In trials examining the response rates to INF-α2b, the 5 year relapse-free survival among patients with stage II and III melanoma has been reported to be between 37-44 %. (Kirkwood, Strawderman, Ernstoff, et al., 1996; Kirkwood, Ibrahim, Sondak, et al, 2000; Kirkwood, Ibrahim, Sosman, et al, 2000). The primary barriers in the use of INF-α2b are the adverse side effects.

The FDA has also approved the use of interleukins (IL-2) in cancer therapy, which act by increasing the activity of cytotoxic T cells which can both identify and destroy cancer cells (Mocellin, Panelli, Wang, Rossi, & Marincola, 2002). While general response rates to treatment to IL-2 treatment are moderate, IL-2 has been found to be an effective treatment for cancers, such as renal cell cancer and melanoma, which historically respond poorly to conventional treatment (Kintzel & Calis, 1991). The usefulness of monoclonal

antibodies has also been examined. In two recent reviews of the developments in the area of immunotherapy (Jurcic & Scheinberg, 1994; Cheng, Rieger, von Mehren, Adams, & Weiner, 2000) authors concluded that trials examining the effectiveness of radiolabeled MoAbs have produced positive results.

Diet

Adhering to a healthy diet is not only a preventive factor: consuming a healthy diet during cancer treatment has been associated with an increase in the body's ability to tolerate treatments in two ways. As stated previously some common side effects of cancer treatment encompass both food aversion and anorexia. Thus, malnutrition during cancer treatment is common and a real concern. Following a proper diet has been shown to reduce the chances of malnutrition by ensuring the presence of important nutrients. Second, certain nutrients have been associated with improved immune status (Lowell, Parnes, & Blackburn, 1990; Simone, Simone, & Simone, 1997). Specifically, studies have suggested that the both omega-3 polyunsaturated fatty acids and the amino acid arginine may significantly enhance immune function (Lowell, Parnes & Blackburn, 1990). In a study examining the effects of nutritional supplements in late stage cancer (See, Mason, & Roshan, 2002) results revealed a positive effects of the addition of milk whey protein, ascorbic acid, Immune Modulator Mix (a combination of vitamin, minerals, antioxidants and immune-enhancing natural products) and soy extract on titers of natural killer cells and tumor necrosis factor alpha. The underlying mechanisms of these findings are still being investigated but some researchers have suggested that the nutrient effects

may affect the expression of specific genes, especially cytokine and cytokine receptor expression (Sanders & Kline, 1995).

Exercise

Similar effects have been found in relation to physical activity. Other studies of the effects of physical exercise on quality of life in cancer patients have found that participation in an exercise program during hospitalization was significantly correlated with several quality of life measures such as physical well-being, psychological well-being, depression, anxiety and number of days hospitalized. (Courneya, Keats, & Turner, 2000; Block, 2000; Simone, Simone, & Simone, 1997; Dimeo et al, 1996). Specifically exercise has been found to reduce the severity and duration of side effects such as fatigue, neutropenia, thrombocytopenia, diarrhea, and pain (Dimeo, Fetscher, et al, 1997; Mustian, Katula, and Gill, 2002; Mock et al, 2001). One study also found that moderate exercise during inpatient treatment reduced the length of hospitalization (Dimeo, Tilmann, et al, 1997). In a review (Nieman, 1997) of exercise immunology, data suggests that the incidence and mortality rates for certain types of cancer are lower among patients who remain physically active and that exercise may increase the rate of with which white blood cells (macrophages, NK cells, and lymphocytes) circulate the lymphatic system.

Tobacco use

Research examining the effects of continued tobacco use after diagnosis of cancer has produced disturbing results. Not only are cancer patients who continue to smoke at an increase risk for relapse and secondary malignancies, smoking can also negatively impact treatment by significantly reducing the effectiveness of treatment. In a study of patients

with head and neck cancer, Browman et al (1993) found that the rate of complete response to radiation therapy was 45% among patients who continues to smoke compared to 74% for those who did not smoke during treatment. In addition patients who continued to smoke during treatment also had a significantly poorer two-year survival rate (39% versus 66%). Similar results were observed in another study of patients with carcinoma of the bladder (Flesher et al, 1999). Here authors found a significant decrease disease free survival time among continued smokers compared to quitters and ex-smokers. Other studies have supported these results. In a study investigating the effect of nicotine on the cytotoxic effects of anticancer agents (Onoda et al, 2001) results indicated that nicotine adversely affects the ability of anticancer agents to kill of cancerous cells. Research focusing on the risk of developing secondary malignancies among continued smokers has found that both prolonged and intense smoking prior to diagnosis as well as continued smoking after diagnosis greatly increases the odds for secondary cancers or relapse (Day, Blot, Shore, MacLaughlin et al, 1994).

Alcohol use

Alcohol use has also been established as a potent risk factor in the development of cancer. Studies examining the effect on treatment outcomes among cancer patients who continue alcohol use after diagnosis suggests that the risk of developing secondary malignancies is higher among these patients than among non-drinking patients (Day, Blot, Shore, MacLaughlin et al, 1994). In a review (Wynder, Mushinski, & Spivak, 1977) of the relationship between tobacco and alcohol consumption and the development of additional primary cancers of the upper alimentary tract (oral, oral-pharyngeal, larynx,

and lung cancers) authors concluded that chances of developing a second primary malignancy (i.e. relapse) is dependent principally on the intensity (i.e., quantity and duration) of alcohol consumption prior to diagnosis. These results were consistent with the finding of Day, Blot, Shore, MacLaughlin et al (1994) that alcohol use is a risk factor for secondary malignancies.

Summary

In conclusion, adherence to the recommended cancer treatment regimen is highly correlated with clinical outcomes among cancer patients. It should be noted here, that what denotes an effective dose varies depending on type of cancer and stage of illness, and there is a wide range of individual variability in response rates to what is normally considered effective doses or treatments. Despite evidence that most cancers can be treated successfully with standard treatment modalities such as surgery, chemo, radiation, or immunotherapy, treatment adherence rates vary greatly. This chapter has provided a brief review of the epidemiology and biology of cancer, cancer treatment modalities and cancer treatment outcome. The next chapter will review the concept of adherence, adherence rates to the different forms of cancer treatment, and predictors of adherence to cancer treatment.

CHAPTER 2: PREDICTORS OF CANCER TREATMENT ADHERENCE

A brief discussion of the concept of treatment adherence serves as an introduction to this chapter. Following the introduction, adherence rates among cancer patients to chemotherapy, radiotherapy, diet, exercise, and tobacco/alcohol cessation are considered. The second section of the present chapter reviews predictors of adherence that have been proposed in the literature such as those relating to type and stage of cancer, demographic variables, and psychosocial components.

The Concept of Adherence

Before discussing treatment adherence and predictors of treatment adherence in the context of cancer it is important to briefly review the definition of medical treatment adherence. In the medical literature treatment adherence has been defined as "the degree to which a patient 'voluntarily' follows the (treatment) regimen recommended by a (health care) provider" (Barofsky, 1984). Inherent in this definition is the point that treatment adherence involves *both* the health care provider and the patient.

Traditionally, adherence to treatment has been viewed as a necessary step in reaching remittance of disease state and, hopefully, long term survival by the patient (Peterman & Cella, 1998; Lewis, Linet, & Abeloff, 1983). This is also the view held by many health care providers as this is consistent with their job description. Thus, a patient who fails to follow through with all recommendations may be labeled as 'non-adherent'. The health care provider perspective often assumes that patients will adhere to treatment recommendation 100% as the patient is viewed as the primary beneficiary of adherent behavior. However, research has found that among chronically ill patients the perspective

on adherence is more related to the notion of 'doing one's best' under the circumstances (Roberson, 1992). Further, patients often defined adherence in the context of their life (i.e. actual ability to follow through with recommendations) as well as their perception of what is reasonable and effective (Roberson, 1992).

Recently, researchers have begun to examine possible predictors and correlates of cancer treatment adherence. To date most research on treatment adherence in the context of cancer has focused primarily on two questions. One area of research has examined the medical and health related consequences of poor adherence, while another area has been aimed toward the development of ways to measure adherence and, subsequently, the measuring of actual adherence rates among cancer patients (Peterman & Cella, 1998).

Adherence to Cancer Treatment

Adherence to Chemotherapy

Studies examining adherence to chemotherapy have suggested that overall approximately 8% of patients fail to complete the recommended regimen of chemotherapy (Blay et al, 1995; Brown et el, 1994; Moertel et al, 1990; Taylor, Lichtman, & Wood, 1984). In addition, research suggests that the percentage of patients who fail to complete the entire treatment regimen is even higher. For example, one study of women with breast cancer (Ayres, Hoon, Franzoni, Matheny et al, 1994) found that only 63% of the women kept more than 85% of their scheduled treatment appointments.

Non-adherence with chemotherapy also appears to be higher among patients with late state cancers. For example, in a trial examining the effects of adjuvant chemotherapy in patients with advanced lung cancer it was found that only 54% of patients actually

completed all four courses of recommended chemotherapy (Feld et al, 1993). In two studies of patients with advanced stage leukemia and non-Hodgkin's lymphoma non-adherence was reported to range between 10-15% (Jehn, 1994; Verdonck et al, 1992), and among women with late stage breast cancer non-adherence has been reported to range anywhere from 20-30% (Schumacher et al, 1994; Rivkin et al, 1993).

Recently, oral administration of chemotherapy has become more prevalent. In a review of adherence to oral anti-neoplastic agents by Partridge, Avorn, Wang, & Winer (2002), the authors reported adherence rates ranging from 16.8% to 97.9% depending on type of cancer and the specific agent. This means that anywhere from 2% to 83% of patients could be classified as non-adherent. Similar results were found in a study examining adherence rates, and predictors of nonadherence, in women receiving adjuvant treatment with tamoxifen for breast cancer (Partridge, Wang, Winer, & Avorn, 2003). Authors found that during their first year of treatment, patients filled prescriptions for tamoxifen 87% of the time. However, after four years adherence rates dropped to 50%. This is a significant drop considering that continued use of tamoxifen therapy can prevent recurrence and death in women with early-stage breast cancer.

Radiation Therapy

Relatively few studies have focused on the issue of treatment adherence in the context of radiation therapy. In a study by Hyland et al (1983) the authors suggest that non adherence to radiotherapy may take the form of delay in seeking treatment, refusal of treatment recommendations, premature termination of treatment, and no show for post treatment follow-up appointments.

Studies examining actual adherence rates to radiotherapy among cancer patients suggest that adherence rates among patients receiving radiotherapy are moderate. For example, in a study of adherence to recommended radiation therapy among head and neck cancer patients 47% were found to be compliant (Cathcart, Dunican, & Halpern, 1997). Similarly, in a study of women with cervical cancer (Formenti, Meyerowitz, Ell, Muderspach, Groshen, Leedham, Klement, & Morrow, 1995) results suggested that up to 60% of patients failed to complete the regimen of radiation therapy. In another study examining adherence rates and clinical outcome among rural women undergoing radiation therapy for early stage breast cancer (Li, Brown, Ampil, Burton, Yu & McDonald, 2000), the authors reported that only 36% of the patients were fully compliant, i.e. they completed the entire course of radiation therapy and all clinical follow-up appointments

Diet

The benefits of maintaining a low fat high fiber diet in cancer prevention and control are well established. No one study has examined the adherence to such a diet among cancer patients in general. However, several randomized trials examining adherence among different experimental conditions have found that adherence among participants receiving an intervention targeting diet is higher than adherence among controls. In one such study of 240 women who had been operated for a stage I-II breast cancer (Holm, Nordevang, Ikkala, Hallstrom, & Callmer, 1990). 121 were assigned to an intervention group receiving dietary counseling to reduce dietary fat and 139 were assigned to a control group which received no dietary advice. All patients were followed for two years.

Patients in the intervention group decrease their fat intake by 14% vs. 3.6% in the control group suggesting that the intervention increased overall adherence to the recommended diet. However, even among the patients in the intervention group only 52% followed through with the dietary regimen for two years.

In an overview of adherence to preventive dietary regiments in the general public (Brownell & Cohen, 1995) authors concluded that there is evidence that meaningful dietary changes can be made and continued adherence to these is possible. However, the authors caution that adherence is influences by several variables such as psychological, cultural, environmental, and behavioral factors that may interfere with patients' ability and willingness to change their diet.

Exercise

A few studies have examined exercise adherence among cancer patients. A pilot study examining adherence to a moderate-intensity exercise program in women receiving chemotherapy or radiation for breast cancer (Pickett, Mock, Ropka, Cameron, Coleman, & Podewils, 2002) found that 30-50% of women failed to adhere to the recommended exercise regimen. The best predictor of adherence to the exercise regimen turned out to be regular exercise prior to the diagnosis. This finding was supported in another study examining exercise adherence rates among cancer survivors (Courneya, Friedenreich, Sela, Quinney, & Rhodes, 2002). In another study examining the influence of exercise discussions during cancer treatment consultations on actual adherence, Jones & Courneya (2002) found that patients whose physician had initiated discussions about exercise were

much more likely to exercise regularly. Results also revealed that only about 25% of physicians actually discussed the importance of exercise with the patients.

Tobacco and Alcohol Use

Tobacco use is particularly prevalent among head and neck cancer patients. Several studies have examined the rates of smoking cessation among these patients. In a study of 48 patients with advanced head and neck cancer scheduled for radiation therapy Des Rochers, Dische, and Saunders (1992) found that no less than 72.9% were smoking at the time of diagnosis and that 51% of these patients continued to smoke after diagnosis. Another study by Browman et al (1993) found that among 115 head and neck cancer patients being treated with radiation therapy 46% continued to smoke during treatment. A more recent study examined smoking rates among stage III and IV lung cancer patients enrolled in a trial of combined radiation and chemotherapy (Cox et al, 2002). Among 226 patients, 215 (95%) of patients had a history of cigarette smoking. Among these 69% stopped smoking prior to entry in the trial and 9% stopped smoking at some point during the course of the trial; however, 11% continued smoking throughout the trial. Authors noted that while a majority of lung cancer patients were able to stop smoking, a notable subset of patients continued smoking despite diagnosis of lung cancer, enrollment in a clinical trial, treatment-related toxicity, and encouragement from clinicians to stop smoking.

While elevated alcohol use has been implicated as a potent risk factor for cancer, in particular among patients with head and neck cancer, no studies to date have examined the extent to which alcoholic patients are able to reduce their use of alcohol or completely

abstain in the context of cancer. However, one study (Duffy, Terrell, Valenstein, Ronis, Copeland, & Connors, 2002) examining the relationship between smoking, alcohol intake, depressive symptoms and quality of life in head and neck cancer patients found that results showed that 35% of the respondents had smoked within the last 6 months and 46% had drunk alcohol within the last 6 months. Interestingly, whereas 32% of smokers were interested in smoking cessation services, only 9% of those who drank alcohol expressed interest in alcohol services. Furthermore, other studies have suggested that patients who are alcoholics are at an increase risk for co-morbid psychiatric disorders which in turn been associated with poor treatment adherence among cancer patients (Lundberg & Passik, 1997).

The next section of the present chapter provides a review of predictors of treatment adherence that have been proposed in the literature.

Predictors of Treatment Adherence

It is clear that no one factor predicts whether a cancer patient will choose to adhere to treatment recommendations and while the research on predictors of adherence to cancer screening is substantial, there is a paucity of research examining predictors of cancer treatment adherence. Such literature as does exist will be presented here.

Demographic Predictors

The financial ramifications of cancer can be significant, particularly for patients without insurance and low-income patients who cannot afford the loss of wages. A study exploring factors that may affect medical information seeking, treatment engagement, and emotional adjustment among African American cancer patients, found that lack of

insurance was a significant predictor of poor adherence (Matthews, Sellergren, Manfredi, & Williams, 2002). Similar studies of other medical populations have suggested that patients with incomes below the poverty level are at higher risk for cost-associated non-adherence and that patients without insurance are significantly more likely to fail to adhere than those with insurance (Kennedy & Erb, 2002; Rudman, Gonzales, & Borgida, 1999). In a study examining rates of adherence among low-income minority women with abnormal screening mammograms women who did not comply with follow up appointments cited loss of wages as a reason for non-adherence; however, insurance did not differentiate between compliant versus non-compliant women (Rojas, Mandelblatt, Cagney, Kerner, & Freeman, 1996).

Accessibility to treatment is another potential barrier to treatment. With the centralization of cancer care, concerns about the impact of travel on treatment adherence have emerged. A recent literature review (Payne, Jarrett, & Jeffs, 2000) examined the impact of travel on cancer patients' experiences of treatment. Authors concluded that, while travel may be inconvenient and distressing to many patients, the lack of research in this area (only 11 studies were deemed appropriate for inclusion in the review) makes it impossible to draw any conclusions about the impact of travel on treatment adherence among cancer patients. However, another study found that patients who were referred to a local hospital were more likely to complete treatment than those who were referred elsewhere (Simmons and Lindsay, 2001).

Age has also been proposed as a possible predictor of treatment adherence. However, due to the skewed distribution of cancer (cancer is much more prevalent in the above 60 yr. population) few studies have examined the moderating effect of age in the context of

cancer treatment adherence. In one such study of women receiving tamoxifen therapy for early stage breast cancer (Partridge, Wang, Winer, & Avorn, 2003) results indicated that adherence was lowest among the very young and the very old patients. Similar results have emerged among other medical populations (Rudman, Gonzales, & Borgida, 1999). However, the influence of age on treatment adherence is at best inconclusive. Other studies examining the predictors of medical adherence have found support for several other variables such as race, drug and dosage form, number of medications, cost of medications, insurance coverage, and physician-patient communication, but failed to show any effect of age on adherence (Balkrishnan, 1998; DiMatteo, Hays, & Sherbourne, 1992).

Educational level has been associated with treatment adherence among cancer patients. Siminoff and Fetting (1991) conducted a study examining the decision-making process of 100 breast cancer patients and their physicians. They found that a majority (80%) of patients accepted their physician's primary treatment recommendation, but surprisingly, results revealed that patients who were better educated and who tended to be risk takers were less likely to comply with primary treatment recommendation. This is contrary to the findings in the cancer screening literature where higher education has been associated with better adherence to screening recommendations. However, results from another study, which examined the predictors of medication adherence among patients with asthma, renal disease, cardiac disease, or cancer, (Horne & Weinman, 1999) indicated that while specific beliefs about medicines were related to reported adherence, there was no effect of educational level on reported adherence.

Data on the role of ethnicity on cancer treatment adherence is scarce. One study examining adherence rates among women diagnosed with early stage breast cancer (Partridge, Wang, Winer, & Avorn, 2003) found that non-white patients had lower adherence rates than white patients. However, another study examining adherence rates among minority women with breast cancer (Li, Brown, Ampil, Burton, Yu, & McDonald, 2000) did not find any relationship between ethnicity and treatment adherence. Research on the interaction between ethnicity and treatment adherence in other areas has shown similar results. For example, in a study of adherence to anti-depressive medications (Sleath, B., Rubin, R., & Huston, S. A., 2003) results revealed that Hispanic patients were significantly less adherent to antidepressant therapy than non-Hispanic white patients. Another study (Oggins, 2003) investigated the difference in reasons for adherence to medication for HIV between ethnic minority groups and European Americans. Misinformation about the illness and medications were more prevalent among minority groups than European Americans. However, a similar study of racial differences in patient-perceived barriers and reported antiretroviral medication adherence (Ferguson, Stewart, Funkhouser, Tolson, Westfall, & Saag, 2002), found no differences on adherence among different racial groups.

Gender differences have been proposed as a possible predictor of adjustment to illness and treatment adherence. No one study has compared adherence rates among men and women with cancer. This may be due, in part, to the paucity of research examining adherence rates in cancers other than breast and prostate cancers, which are, by nature, restricted to one sex or the other. A few studies, however, have examined gender differences in psychological reactions to cancer diagnosis and cancer treatment. These

studies have suggested that women tend to report more overall psychological distress than men (Hampton & Frombach, 2000) and that men and women report distress in different areas (Peleg-Oren & Sherer, 2001). As both psychological distress and psychiatric co-morbidity have been associated with poor adherence, gender differences in psychological state may be meaningful, but indirect, predictors of treatment adherence

Summary

In summary, research examining the influence of demographic variables on cancer treatment adherence has been inconclusive. Demographic variables, such as financial barriers, educational level, and ethnicity, have been found to have some association with cancer treatment adherence, however, more research is needed to better understand the underlying mechanisms of how these variables affects patients' decisions to adhere to cancer treatment recommendations.

Diagnosis- and Treatment-Related Predictors

Among other medical populations side effects have been cited as a primary reason for non-adherence (Kennedy & Erb, 2002). For example, in a study of renal transplant patients, side effects of medications were found to be a strong predictor of non-adherence (Rudman, Gonzales, & Borgida, 1999). However, while side effects of many cancer treatments are highly adverse and often result in marked physical discomfort, psychological distress, and poor quality of life (QOL), non-adherence due to side effects is surprisingly low among cancer patients (Richardson, Marks, & Levine, 1988; O'Connor, Boyd, Warde, Stolbach, & Till, 1987). For example in a study of medication preferences among cancer patients (O'Connor, Boyd, Warde, Stolbach, & Till, 1987)

revealed that patients' pre-treatment preferences for specific anti-neoplastic agents were not influenced by the way information about side effects was presented and, further, despite significant toxicity following initiation of treatment, patient preferences remained consistent during treatment. Similarly, another study found that neither the occurrence or frequency of side effects, nor the difficulty dealing with any of these, related to non-adherence with anti-neoplastic medications among cancer patients (Richardson, Marks, & Levine, 1988).

Other diagnostic factors in treatment adherence are type and stage of cancer. Studies examining the role of type of cancer on treatment adherence have provided overwhelming evidence that patients diagnosed with breast cancer show much greater rates of adherence to treatment, usually cited as above 90%, than cancer patients in general among whom adherence rates fall around 70% (Taylor, Lichtman, & Wood, 1984; Simmons, 2001). Adherence rates are typically lowest among cancers that require invasive and prolonged treatment with more than one treatment modality. For example in a study of women with breast cancer receiving adjuvant tamoxifen therapy (Partridge, Wang, Winer, & Avorn, 2003) results revealed significantly lower medication adherence among mastectomy patients than among patients who did not have a mastectomy. In another study by Franciosi et al (2003) examining compliance rates to an alternating chemo-radiotherapy treatment regiment, a highly complex treatment, in patients with advanced head and neck cancer, adherence rates were also found to be poor**.** Other studies examining the effects of multimodal chemo-radiation therapy have also found adherence rates to be lower than with either treatment alone. For example, in two different studies that both examined the efficacy of multimodal treatment among head and neck cancers, non-adherence was cited

to fall around 20-21% (Schuller et al, 2002; Robbins et al, 2000). Moreover, these numbers did not include patients who discontinued treatment due to side effects.

While research has investigated adherence rates among cancer patients with late stage disease, few studies have compared these to adherence rates among patients with stage I or II illness. Results from studies examining the effect of stage on cancer on treatment adherence indicate that stage of cancer is not a significant predictor of adherence to cancer treatment. For example, in a retrospective study of survival rates among patients treated for head and neck cancers (Cathcart, Dunican, & Halpern, 1997), stage of cancer was not predictive of treatment adherence. Specifically, results revealed that the adherence rate among patients with stage III or stage IV was 48%, which was not significantly different from the adherence rate of 54% among the stage I and II patients.

Summary

In conclusion, three variables related to diagnosis and treatment has been consistently associated with cancer treatment adherence. These include the type of cancer, invasiveness of treatment, and intensity of treatment. Breast cancer patients have been found to be more likely to adhere to treatment than patients with other types of cancer. With respect to both invasiveness and intensity of treatment both were negatively related to treatment adherence. The more invasive and the more intense the treatment, the less likely patients were to adhere. To this point, the roles of cancer treatment side effects and stage of cancer in relation to cancer treatment adherence remain unclear.

Psychosocial Predictors

Given the significant impact of cancer and cancer treatment, researchers have begun to investigate psychological variables, such as co-morbid psychological disorders and social support, as possible predictors of cancer treatment adherence. This section will provide a brief review of psychosocial predicators.

Psychological Disorders

Studies examining psychiatric co-morbidity as a predictor of treatment adherence have provided mixed results. In one longitudinal study examining the role of psychiatric complaints on treatment adherence among patients with head and neck cancer (Girardi, de Pisa, Cianfriglia, Perrino, et al, 1992), neither somatic disturbance, anxiety, insomnia, social dysfunction, nor depression predicted treatment adherence. However, other studies have provided evidence that psychiatric co-morbidity does indeed affect adherence with treatment. Researchers have examined the effect of co-morbid depression, psychoses, cognitive impairment, interpersonal dysfunction, and addiction in relation to treatment adherence (Kunkel, Woods, Rodgers, & Myers, 1997; Seddon, Zabora, & Smith, 1992; Goldberg, 1983). Results from these studies have confirmed that both psychological and psychiatric complaints appear to be linked with poor adherence.

Interestingly, in a study of oncologists' views of cancer patient non-adherence (Hoagland, Morrow, Bennett, and Carnrike, 1983) doctors, themselves cited psychological problems as a prime determinant for non-adherence. Consistent results have emerged from a study examining the influence of mood and adjustment to cancer on adherence with chemotherapy among breast cancer patients (Ayres, Hoon, Franzoni,

Matheny, et al, 1994). Findings suggested that non-adherence (defined as keeping fewer than 85% of appointments) was related to high scores on measures of guilt and hostility. In another study examining adherence to chemotherapy (Gilbar, 1989) results suggested that patients who were non-compliant tended to report significantly more adjustment problems in a variety of areas. Specifically, subjects who dropped out of treatment were less adjusted and reported more distress than patients who completed treatment. Recent studies have focused on the early detection of psychiatric symptoms and appropriate treatment and intervention to eliminate these potential barriers to adherence and to increase patients' psychological well-being (Kunkel, Woods, Rodgers, & Myers, 1997; Seddon, Zabora, & Smith, 1992).

Other research has focused on the psychological impact of cancer on patients in contrast to psychiatric disorders (Cohen 2002; Cull, 1990). Results have suggested that the psychological impact of the cancer experience is significant and often traumatic (Eakes, Rakfal, Keel, & Gaiser, 1996). In a study examining the self-reported spiritual and existential needs among cancer patients (Moadel et al, 1999) found that patients desired help in overcoming fears, finding hope, talking about peace of mind, finding meaning in life, and finding spiritual resources, as well as someone to talk to about the meaning of life and death.

Social Support

The cancer screening literature has provided consistent evidence that social support plays a significant role in people's decision to follow through with recommended cancer

screening procedures. However, most research on social support among cancer patients has focused on the effect of social support on patient adjustment.

In a study of breast cancer patients and their spouses, Ben-Zur, Gilbar, & Lev (2001) found that the use of emotion-focused coping by the spouse was negatively related to the patient's distress and psychological adjustment, indicating that coping and adjustment of the patient happen within a dynamic and interactive social network. Another study of women with breast cancer found that the size a patient's social network was related to greater emotional and instrumental support and that emotional support, but not instrumental support, was predictive of better mental well-being (Bloom, Stewart, Johnston, Banks, & Fobair, 2001). Similarly, in a study of adjustment among Hispanic women undergoing treatment for breast cancer Alferi, Carver, Antoni, Weiss, and Duran (2001) found that emotional support from friends and instrumental support from spouses at pre-surgery predicted lower distress post surgery.

The context of patients' social environment has also been linked to patient coping. In a study examining the effect of spouse support, coping, and mood among individuals with cancer, results indicated that spouse criticism was associated with avoidant coping strategies on behalf of the patient, whereas spouse support was associated with adaptive coping (Manne, Pape, Taylor, & Dougherty, 1999). These findings were supported by a study of prostate cancer patients in which the associations between coping and adjustment were found to depend on patients' perception of support (Ptacek, Pierce, & Ptacek, 2002). Patients who perceived high levels of support reported more problem-focused coping and higher levels of support-seeking as well as less self-blame, wishful thinking, and avoidant coping.

While research has suggested that social support is central in psychological adjustment and adaptive coping among cancer patients, there is very little research examining the role of social support in predicting treatment adherence. Extensive literature searches resulted in only one such study by Gilbar (1990) who found no relationship between family environment and patients' adherence to chemotherapy.

Summary

In summary, psychological co-morbidities, such as depression, anxiety, and psychosis, has been found to be strong predictors of non-adherence. Results from studies examining the role of social support on treatment adherence have been unclear. These results may, in part, be a reflection of the relatively few studies that has explored the relationship between coping and treatment adherence. One source supporting further research into the role of coping on treatment adherence is evidence from the cancer screening literature, which have suggested that social support is instrumental in adherence to recommended cancer screening.

The next chapter will present the present study and discuss key variables in the proposed model.

CHAPTER 3: PRESENT STUDY

The current chapter provides a review of the epidemiology, biology, etiology, and treatment of head and neck cancers. An overview of the literature on adherence to primary medical intervention, tobacco and alcohol cessation, and oral hygiene among head and neck cancer patients will ensue. Then, the proposed model to be examined will be presented followed by a discussion of key variables in the model: Doctor-patient communication, patients' coping, and patients' illness perceptions.

The present study examines several factors that may influence head and neck cancer patients' consistency in following the prescribed oral care program and cessation of tobacco and alcohol use. These three terms will hereafter be collectively referred to as "oral health regimen" no to be confused with "oral care program" which denotes oral hygiene only.

Common to all of the head and neck cancers is the use of radiation therapy both as initial and adjuvant treatment. Besides the more general side effects associated with radiotherapy, head and neck cancer patients being treated with radiotherapy often endure additional complications involving the oral cavity and surrounding areas (Dreizen, 1990). These complications arise from damage to fast growing cells in the mucosal tissue and salivary glands. Complications include mucositis, which is the thinning of the mucosa in the radiation field, pain, mucosal fibrosis and atrophy, salivary gland dysfunction, increased risk of dental caries, increased susceptibility to infections, tissue necrosis, taste dysfunction, and muscular and/or cutaneous fibrosis (Silverman, 1990, Chambers, Toth, Martin, Fleming, & Lemon, 1995).

It is estimated that most, if not all, head and neck cancer patients being treated with radiation therapy will develop oral complications (Dreizen, 1990, Chambers, Toth, Martin, Fleming, & Lemon, 1995). As a consequence of these complications head and neck cancers patients who are being treated, or have been treated, with radiation therapy are required to follow a strict oral care program for the rest of their lives. Further, use of tobacco and/or alcohol during and after treatment can exaggerate the complications in addition to significantly increase chance of secondary malignancies.

Head and Neck Cancers

Epidemiology

About 3% percent of all cancers are head and neck cancers meaning that around 30,000 individuals in the US are diagnosed with head and neck cancer each year (Cancer Prevention & Early Detection, 2001; Silverman, 2001). Unfortunately, despite advances in surgery, radiation therapy, and chemotherapy five-year survival rates among head and neck cancer patients remain low at 50-55% (Silverman, 2001). This is a number that has not significantly improved for decades. The death rate for oral cancer is higher than that of cervical cancer, Hodgkin's disease, cancer of the brain, liver, testes, kidney, ovary, or skin cancer (malignant melanoma). Oral cancers are particularly dangerous because the risk for second, primary tumors is high. In other words, patients, who survive a first encounter with the disease, have up to a 20 times higher risk of developing a second cancer (Spitz, 1994; Day, Blot, Shore, Schoenberg et al, 1994).

Head and neck cancers are more common among middle aged and older individuals, and a majority of people diagnosed with these cancers are over the age of 40 at the time

of discovery, though head and neck cancers do occur in younger populations. Men are twice as likely as women to develop oral cancers (Swango, 1996) though this ratio is starting to even out, most likely due to the fact that women are increasingly exposing themselves to risk factors such as tobacco and alcohol use. These cancers tend to occur twice as often in the black population as in whites, and survival statistics for blacks over five years are also poorer at 33%, versus 55% for whites. This difference is most likely due to socio-economic factors such as income levels, education, and availability of proper health care.

Biology of Head and Neck Cancer

Head and neck cancers encompass cancers of the lips and oral cavity, paranasal sinuses and nasal cavity, salivary glands, oropharynx, nasopharynx, hypopharynx, larynx, and lymphnodes in the upper part of the neck. The images below provide an illustration of the potential cancer cites in head and neck cancers.

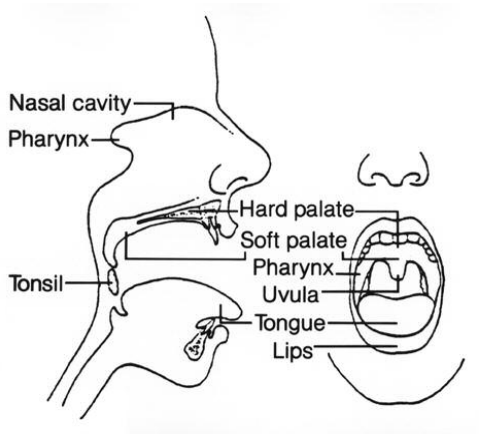

Image 1: Potential cancer sites of the oral cavity.
Downloaded from National Cancer Institute's website

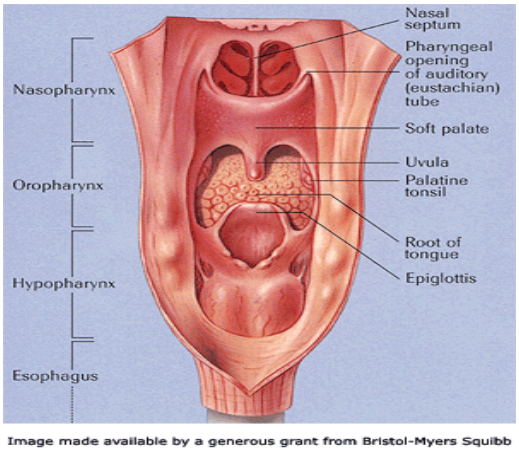

Image 2: Potential cancer sites in the neck and posterior oral cavity
Downloaded from www.hncancer.com

Most head and neck cancers are of the squamous cell variety (90%). Squamous cells are found in the tissues that forms the surface of the skin, the lining of the hollow organs of the body, and the mucosal lining of the passages of the respiratory and digestive tracts (Silverman & Shillitoe, 1998). Early oral cancers and precancerous lesions are often subtle and asymptomatic. These lesions tend to appear as white or red patches on or around the lips, gums, palate, tongue, tonsils, and floor of the mouth, or as smalls indurated ulcers, which looks like common canker sores (Silverman & Shillitoe, 1998). Later stage oral cancers may take the form of non-healing ulcers and symptoms may develop into bleeding, loosening of teeth, dysphagia (the sensation that food isn't progression normally from the throat to the stomach), dysarthria (speech problems due to inability to coordinate the muscles of the mouth), odynophagia (pain when swallowing), numbness in the oral/facial region, or the development a lump or mass which can be felt inside the mouth or neck.

The severity of head and neck carcinomas are determined based on the TNM system (Fleming, I. D. et al, 1997), which encompasses four stages. Stage I and II cancers are considered early stage cancers and generally have a good prognosis with proper treatment. These cancers are characterized by tumors that are no more than 4 cm in dimension and show no evidence of either lymphnode involvement or distant metastasis. Stage III and IV cancers are advanced cancers and the prognosis varies depending on the size of tumor, spread to lymphnodes and distant metastasis. Stage III cancers are characterized by tumors greater than 4 cm in dimension, or tumors greater than 2 cm in dimension with a metastasis (3 cm or less) to a single lymphnode. Stage IV cancers involves a) tumors that invade adjacent structures with or without lymphnode

involvement or any size tumor with metastasis (3-6 cm in dimension) to either a single lymphnode or metastasis to more than one lymphnode, b) any size tumor with lymphnode metastasis greater than 6 cm in dimension, or c) any size tumor with or without lymphnode involvement but with distant metastasis.

Risk Factors

Primary risk factors for head and neck cancers are tobacco use and alcohol use. It is estimated that 85% of head and neck cancers can be linked to past and/or current tobacco use, and the risk of developing cancers of the head and neck are 5-9 times higher among smokers than non-smokers (Mashberg, Boffetta, & Winkelman, 1993; Jovanovic, Schulten, Kostense, Snow, & van der Waal, 1993). Further, among patients treated for head and neck cancer who continue to smoke, chances of developing secondary malignancies are 2-6 times higher than among patients who stop smoking at diagnosis (Silverman & Shillitoe, 1998).

Alcohol use has been identified as another significant contributing factor in head and neck cancers. Research has found that, when controlling for smoking, moderate to heavy drinkers have a 3-9 times greater risk of developing oral cancer (Mashberg, Boffetta, & Winkelman, 1993; Jovanovic, Schulten, Kostense, Snow, & van der Waal, 1993). While each of these behaviors are significant risk factors on their own, studies examining the combined effects of smoking and alcohol use have found a 15 times greater risk of developing oral cancer among those who both smoke and drink compared to those who neither smokes nor drinks. Among individuals who are both heavy smokers and heavy drinkers this risk increased by 100 times (Blot et al, 1988).

Other risk factors for head and neck cancer include chronic sun exposure (cancer of the lips), poor oral hygiene, and dietary factors such as little intake of vegetables and fruits (Winn, 1995; Spitz, 1994). Biological factors include viruses and fungi, such as the human papilloma virus (HPV) and lichen planus, an inflammatory disease of the oral soft tissues.

Treatment

Oral cancer is a preventable disease, related to behavioral and lifestyle factors, including tobacco and alcohol, and prevention and early detection of oral cancer remain the goals of national efforts to reduce the impact of this disease on the public (Day, Davis, et al., 2003). While early detection is readily available through direct examination of the oral cavity during routine dental visits, these cancers are typically not detected in the early stages. This is often due to a combination of dentists not performing this brief examination, and patients failing at getting regular dental exams.

Treatment modalities

Standard treatment modalities for head and neck cancers are surgery, and/or radiation. Surgical treatment is the mainstay of therapy for patients with oral cancer, particularly in advanced stages of cancer. External beam radiation therapy has been used successfully as the primary modality for treating patients with early stage oral cancer, and is also the standard adjuvant therapy in surgically treated patients with advanced stage oral cancer. There is an emerging trend for the use of chemotherapy in combination with radiation therapy and surgery for patients with advanced, recurrent, and metastatic head and neck cancer, although evidence is limited regarding survival benefit. Treatment of head and

neck cancers is usually a multidisciplinary approach involving the efforts of surgeons, radiation oncologists, chemotherapy oncologists, dental practitioners, nutritionists, and rehabilitation and restorative specialists (Harris, Sessions, & Hong, Eds., 1998).

Treatment phases

The standard treatment schedule for head and neck patients consist of a number of different phases. The first phase is the initial work-up, which includes a review of laboratory results, assessment of current symptoms, present illness, treatment, and past medical history, along with a general medical examination, an examination of the head and neck area in addition to any imaging tests deemed appropriate.

When the initial work-up is concluded, a phase of expert consultation ensues. Patients are examined by a dental oncologist to determine the patient's oral health status, and any dental treatments or interventions deemed necessary are performed. Consultations with head and neck surgery and radiation oncology follows to determine the most appropriate treatment. Depending on the site of cancer and expected treatment consequences, patients may also meet with speech pathologists and/or plastic surgeons. Finally, a pre-operative consultation with internal medicine covers nutrition, smoking cessation, and other medical conditions to be considered during treatment.

The next phase is the treatment phase. If appropriate, neo-adjuvant radiation or chemotherapy is given to shrink the tumor. Primary treatment follows and typically involves a combination of surgery and/or radiation. If indicated, adjuvant therapy in the form of radiation or chemotherapy may be given. Once treatment has been successful, regular follow-ups are scheduled to assess recurrence of the primary tumor or the

development of secondary tumors. During the first year patients are scheduled for follow-up exams every 3 months, during the second year every 4 months, during the third year every 6 months, and then once annually.

Treatment of early stage cancers

Early cancers (stages I and II) are highly curable (cure rates fall between 90% and 100%) by surgery, radiation therapy, or a combination of the two (Jones et al, 1992). The choice of treatment is usually dictated by the anticipated functional and cosmetic consequences of treatment and efforts are made to minimize these to the extent it is possible (Cummings et al, 1998; Wang ed, 1990). Patients with cancers treated in the early stages usually have little post treatment disfigurement.

Treatment of advanced stage cancers

Standard treatment for Stage III and IV is similar to treatment for early cancers and usually involves a combination of surgery and radiation therapy. In this case, however, the determination of treatment regimen is based on the exact tumor site as opposed to cosmetic considerations. Cure rates for advanced head and neck cancers are much lower than cure rates for early stage cancers and fall around 50-60%. In some cases, neo-adjuvant chemotherapy is given to shrink tumors, thereby rendering them more definitively treatable with either surgery or radiation (Cummings et al, 1998). However, research supporting the use of neo-adjuvant chemotherapy in head and neck cancers is scarce. In a meta-analysis of 63 randomized prospective trials published between 1965 and 1993 authors concluded that there is a lack of evidence of any survival advantages among patients with advanced head and neck cancers receiving neo-adjuvant

chemotherapy (Pignon et al, 2000). Ongoing trials may further clarify the role of concomitant chemotherapy and radiation therapy in the management of oral cavity cancer.

Radiation therapy in head and neck cancers

Among patients whose cancer is caught at a later stage, the results of surgical removal of the disease may require reconstruction of portions of their oral cavity or facial features (Harris, Sessions, & Hong, 1998). Adjunctive therapy may be required to assist in speech, chewing of foods, the problems associated with the lack of salivary function, as well as the fabrication of dental or facial prostheses (Harris, Sessions, & Hong, 1998).

The use of radiation therapy both as primary or adjuvant treatment is common among the head and neck cancers. Radiation therapy can be administered by external-beam therapy or interstitial implantation, but for many sites the use of both modalities produces better control and functional results (Harris, Sessions, & Hong, 1998). Besides the more general side effects associated with radiotherapy such as fatigue and nausea, head and neck cancer patients being treated with radiotherapy often endure additional complications involving the oral cavity and surrounding areas (Dreizen, 1990). These complications arise from damage to fast growing cells in the mucosal tissue and salivary glands, and include mucositis, which is the thinning of the mucosa in the radiation field, pain, mucosal fibrosis and atrophy, salivary gland dysfunction, increased risk of dental caries, increased susceptibility to infections, tissue necrosis, taste dysfunction, and muscular and/or cutaneous fibrosis (Silverman, 1990, Chambers, Toth, Martin, Fleming, & Lemon, 1995). The presence of one or more these symptoms are common among

head and neck cancer patients treated with radiation therapy, and may, ironically, cause additional complication such as malnutrition and, in severe cases, delay of treatment.

The Oral Health Regimen

Because of the severity of oral complications caused by radiation therapy to the oral cavity and surrounding areas, good oral health is of utmost importance prior to, during, and after treatment. Prior to treatment initiation all patients undergo a comprehensive dental evaluation, by a dental oncologist, to identify risk factors that may unnecessarily increase severity of acute and permanent complications (Chambers, Toth, Martin, Fleming, & Lemon, 1995). Treatment and prophylaxis is performed where deemed appropriate, and for patients with poor oral health full mouth extraction prior to the initiation of radiation therapy is not uncommon (Jansma et al, 1992). Dentulous patients are then introduced to a comprehensive oral care program which involves brushing and flossing after each meal and at bedtime, daily application of fluoride gel, daily and frequent use of mouth rinse, dietary restrictions, and specific tooth brush care that involves the alternate use of two brushes and daily cleansing of brushes in a chlorine solution (Chambers, Toth, Martin, Fleming, & Lemon, 1995; Jansma et al, 1992).

The chronic nature of some of the oral complications of radiation therapy necessitates the maintenance of the oral care program for the rest of the patient's life along with regular dental exams and cleanings, every three to six months (Jansma et al, 1992). Following the recommended oral care program can significantly reduce the risk of developing oral complications or, at the very least, reduce their severity and duration. Failure to follow through with the recommended oral care program, on the other hand,

can lead to serious consequences such as rotting and loss of teeth, periodontal disease, inflammation and infection of facial bone structures, and bone loss (Dreizen, 1990). An additional and very real concern with oral complications is that high oral toxicity may in some cases complicate treatment and require reducing treatment to a less toxic, but also less therapeutic dose, thus decreasing the curative properties of the cancer treatment and increasing the likelihood of metastasis, relapse, or secondary malignancies (Chambers, Toth, Martin, Fleming, & Lemon, 1995).

Appropriate oral hygiene is not the only recommendation for self-care made to patients with head and neck cancers. One of the primary risk factor for developing cancer of the head and neck is tobacco use, in addition to alcohol abuse which is another contributing factor in head and neck cancers. Both smoking and alcohol cessation is highly recommended to these patients and while most understand the reasons for quitting, many fail to quit after their diagnosis (Schnoll et al, 2003, Silverman, 1990). Continued tobacco and alcohol use significantly increase the risk of relapse and secondary malignancies, and has been associated with lower response rates and shorter survival durations (Browman et al, 1993). Further tobacco and alcohol use can also exacerbate the oral complications associated with radiotherapy.

Adherence to components of the oral health regimen

Studies have examined adherence rates to both primary treatment and supportive health behaviors among head and neck cancer patients. This section will review the literature on dependent variables proposed in this study: Adherence to oral care programs, tobacco cessation, and the discontinuation of alcohol use.

Adherence to Oral Hygiene Recommendations

As mentioned earlier an important part of initial consultations is an assessment of patients' pretreatment dental status. Good oral health is desirable to minimize complications and avoid extractions. In a study of head and neck cancer patients scheduled for radiation therapy Lockhart and Clark (1994) found that among one hundred thirty-one patients the majority of dentulous patients could be classified as noncompliant with routine dental care (76%) and oral hygiene (65%). No less than 97% of patients required some form of dental care prior to treatment, however, 81% of these patients failed to adhere to the recommended treatment. These results suggest that non-adherence to the recommended dental care is a concern even before radiation therapy has been initiated.

Adherence to oral care programs continues to be a problem among head and neck cancer patients after treatment. A retrospective study, assessing adherence to post-radiation therapy dental follow-up in a population of head and neck cancer patients (Toljanic, Heshmati, & Bedard, 2002), found that among 334 patients 170 (51%) failed to receive follow-up dental examinations within the first year post-treatment. A similar study examined adherence to recommended fluoride use among 76 patients who had completed radiation therapy for head and neck cancer (Epstein, 1995). Results of this study indicated that only 40% of patients were seen regularly in the dental clinic of the cancer agency, and overall only 43% reported using fluoride gel regularly (once a day). This number was higher among those who were seen in the dental clinic on a regular basis, 67%, versus 28% among the patients who were not seen on a regular basis. The

study did not find any significant differences between the groups in frequency of tooth brushing and use of dental floss.

In a review of two different potency fluoride gels (Tavss, 1997) results indicated that both were equally effective in preventing caries, however, the stronger gel which could be applied once a day was associated with higher adherence among irradiated head and neck cancer patients compared to the low potency gel which had to be applied twice daily, suggesting that convenience may play an important role in adherence to oral hygiene programs among these patients.

Smoking Cessation and Alcohol Use

Smoking is the primary risk factor for head and neck cancers. However, a substantial number of patients continue to smoke after diagnosis and through treatment. In a review by Cox et al (2002) results of studies examining smoking behavior after diagnosis in head and neck cancer patients indicated that the percentage of patients who continued to smoked range from 25 % to 55%. Results from a prospective study (Silverman, Greenspan, & Gorsky, 1993), which followed head and neck cancer patients for up to 15 years post treatment, found that 58 % of women and 52% of men continued to smoke. The study also found higher rates of recurrence among continued smokers than among quitters. Two retrospective studies using patients' charts to determine smoking status reported that 25 to 35% of head and neck cancer patients who smoked at the time of diagnosis continued to do so (Vander, DiNardo, & Oliver, 1997; Ostroff et al, 1995).

Other studies have attempted to identify predictors of smoking cessation among head and neck cancer. One such study found that physical barriers associated with cancer

treatment that made it difficult or impossible to continue to smoke, and smoking cessation counseling at the time of diagnosis were both good predictors of discontinuation of smoking behavior, whereas heavy alcohol use was a negative predictor of smoking cessation (Vander, DiNardo, & Oliver, 1997). Ostroff et al (1995) found that stage of disease and intensity of treatment predicted post-treatment tobacco use. Specifically patients with less severe disease who underwent less extensive treatment were at increased risk for continued tobacco use. Other factors that have been linked to poor smoking cessation are having relatives at home who smoke, a longer time between diagnosis and assessment, completion of medical treatment, greater nicotine dependence, lower self-efficacy, few quitting pros, low risk perceptions, a high number of quitting cons, fatalistic beliefs, and emotional distress (Schnoll, 2002).

Despite overwhelming evidence that alcohol use poses a threat in the development of head and neck cancers, few, if any, studies have examined the rates of alcohol use among head and neck cancer patients during and after treatment. However, alcohol use has been linked to continued smoking, meaning the patients who drink regularly are less likely to quit smoking upon diagnosis of cancer (Vander, DiNardo, & Oliver, 1997).

Summary

Head and neck cancers encompass cancers of the lips and oral cavity, paranasal sinuses and nasal cavity, salivary glands, oropharynx, nasopharynx, hypopharynx, larynx, and lymphnodes in the upper part of the neck. Approximately 30,000 individuals in the US are diagnosed with head and neck cancer each year. However, despite advances in surgery, radiation therapy, and chemotherapy five-year survival rates among head and

neck cancer patients remain low. Primary risk factors for the development of head and neck cancers are tobacco and alcohol use. Standard treatment of head and neck cancers typically consists of a combination of surgery and radiation therapy. However, radiation therapy to the oral cavity and surrounding areas are associated with serious oral complications that necessitate a complex oral hygiene program for the rest of the patient's life. Discontinuation of tobacco and/or alcohol use is also highly recommended. Unfortunately, adherence rates to the oral care program and the cessation of smoking and alcohol consumption are far from optimal.

Present Study

The present study examines the role of doctor-patient communication (the term "doctor" will hereafter refer to the dental oncologist), patients' coping, and patients' illness cognitions and knowledge about cancer on treatment adherence in the context of cancer. Specifically, the study examines these relationships among patients being treated for head and neck cancer.

The focus on head and neck cancers was chosen for three reasons. First, there is a paucity of research within the area of behavioral medicine mapping the predictors of treatment adherence among head and neck cancer patients. Second, treatment for head and neck cancer can be intense, requiring multimodal interventions, which have been associated with low adherence rates and a high number of unpleasant side effects. Finally, radiation to the oral cavity and surrounding areas has deleterious effects on patients' oral health, and the demands for supportive health behaviors are high for head and neck cancer patients. Considering these circumstances, this study focused

specifically on patient adherence to recommended oral care regimens, as well as patients' abilities to refrain from tobacco and alcohol use, as these present additional risks for complications and relapse.

Rationale

Given the scarcity of research on possible predictors of cancer treatment adherence and the overemphasis on breast and prostate cancers in the cancer adjustment literature, the study examines the predictive value of doctor-patient communication, coping, and illness related cognitions with respect to adherence to an oral health regimen. This study will focus on patients with head and neck cancers as there is a lack of research examining the psychological impact of being diagnosed with cancers that to a certain extent may be self-inflicted primarily through alcohol and nicotine abuse.

Considering the finding that patients often report a lack of knowledge about cancer, their own diagnosis and prognosis as well as poor understanding of the suggested treatment (Chan & Woodruff, 1997) it is suggested that cognitions surrounding cancer, diagnosis, prognosis, and treatment may mediate the relationship between doctor-patient communication and adherence.

In a review of doctor-patient communication, Ong et al (1995) proposed a theoretical framework relating background, communication behaviors, and patient outcome variables. Suggested background variables included culture, the doctor-patient relationship, types of patients and doctors, and disease characteristics. Communicative behaviors encompassed three aspects; instrumental behavior (information sharing), affective behavior (expressing and tolerating affect), and socio-emotional behavior (non-

verbal patient-centered behaviors). Potential patient outcomes were cited as satisfaction with medical consultations, treatment compliance, recall and understanding of information, health status, and psychiatric co-morbidity. Based on a review of the literature the authors suggested a link between background variables and communicative behaviors, which they proposed, might be related to patient outcomes. Another model more specific to the relationship between the doctor-patient relationship and patient outcomes have been proposed by Lepper, Martin, and DiMatteo (1995). This model pertains to the nonverbal exchange between patients and physicians and is based on the expectations for patient involvement on behalf of both patients and physicians. Authors suggest that high patient treatment adherence is most likely in situations where both patient and physician expect patient involvement. A third model, the health belief model, was originally formulated to explain the use of preventive services (Becker, 1974). This model considers patients' perceptions of the seriousness of their illness and the efficacy of the recommended treatment in explaining actual adherence to treatment. The model encompasses the following: 1) the patient's evaluation of his/her health status, i.e. seriousness of illness and perceived vulnerability to being ill and the prospect of a further declining status of health. 2) The patient's perception of the risks and benefits associated with the recommended treatment, and 3) some form of either internal or external cue that prompts the patient to either comply or not comply, with the recommended treatment regiment (Becker & Rosenstock, 1984). None of the three models has been tested so far.

The goal of this study was to closer examine some of the key relationships proposed within these frameworks. Specifically the study aimed to investigate the possible links

between physicians' communicative behaviors, patients' illness conceptions, and specific treatment adherence among head and neck cancer patients.

Proposed Model

The study is a longitudinal investigation of several factors that may influence patients' adherence to the oral health regimen. Figure 1 graphically depicts the proposed model. Doctor-patient interaction encompasses two aspects: instrumental information, related to diagnosis, prognosis, and treatment, and affective quality which a measure of physician interpersonal skills. Patients' illness related conceptions incorporate two areas: beliefs about illness related factors such as diagnosis, prognosis, and vulnerability, and beliefs about treatment related factors such cost vs. benefit of treatment and treatment efficacy. Adherence was measured in three areas: adherence to the oral care program, smoking cessation, and abstinence from alcohol. Adherence in each area will be assessed both subjectively, through self-report, and objectively, through dental exams. Patients' coping style is also examined in this model. Coping style is determined by the ratio of adaptive to maladaptive coping strategies.

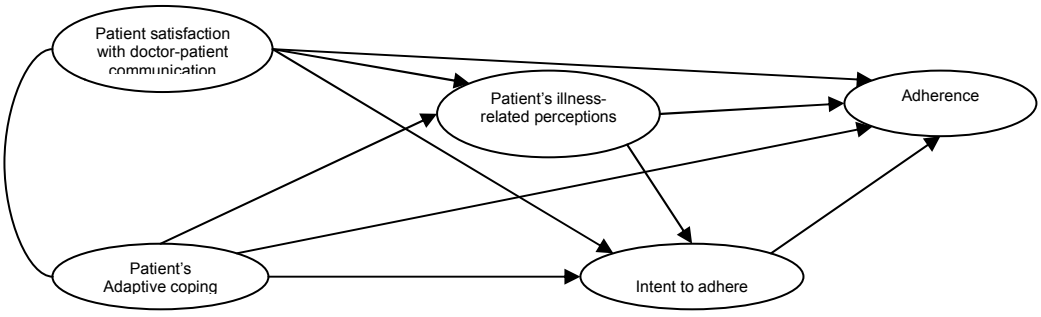

Figure 1. Proposed model.

The variables in the proposed model are reviewed next.

Doctor-Patient Communication

Despite the overwhelming finding that variables related directly to a patient's relationship with their physician along with physician recommendations are among the foremost predictors of adherence to recommended cancer *screening*, very few studies have investigate the relationship between doctor-patient communication and treatment adherence. Most research examining the interaction between doctors and patients in the oncology setting has examined the relationship between communicative behaviors and patients' satisfaction and psychosocial adjustment. The results of this literature will be reviewed briefly below. A discussion of the relatively few studies that has examined doctor-patient communication in the context of cancer treatment will follow.

Doctor-patient communication can be divided into three separate components. The first component encompass what has been termed socio-emotional behaviors and taps physician behaviors such as verbal attentiveness, showing concerns, and negative talk. The second component has to do with the affective quality of the communication, i.e. is the doctor experienced as supportive, understanding, and caring by the patient. The last component is concerned with the kinds and clarity of information that is exchanged during the consultation. For example, is the information about the patient's illness and treatment communicated in a way that is understandable to the patient and is the patient satisfied with the amount of information provided. Each of these aspects of doctor-patient communication is discussed below. Because there is considerable overlap

between the socio-emotional and affective qualities in the research these will be discussed together.

Affective and Socio-Emotional Qualities

In a study examining patient perspectives on patient-health care provider communication among women undergoing chemotherapy for breast cancer Bakker, Fitch, Gray, Reed, and Bennett (2001) found that when rating their satisfaction with the doctor-patient interaction, they placed the most importance on the nature of information exchange. Patients cited positive communication styles as preferable along with feeling a connection with the provider. Similarly, other studies have found that positive experiences resulted from consultations that were characterized by an affective communication style, a comprehensive patient-centered approach and the promotion of a working relationship (McWilliam, Brown, & Stewart, 2000; Ong, Visser, Lammes, & de Haes, 2000; Hebert, Jenckes, Ford, O'Connor, & Cooper, 2001). These characteristics have been rated by patients as increasingly important when the prognosis is poor (Dowsett, Saul, Butow, Dunn, Boyer, Findlow, & Dunsmore, 2000). Research into the specific physician behaviors related to patient satisfaction has suggested that using the patient's first name, ensuring privacy during examinations and consultations, sitting down while talking with the patient, and listening without interrupting were all associated with higher satisfaction.

Satisfaction with the affective quality of doctor-patient communication has been linked with improved short-term psychological adjustment among patients. In a study of the usefulness of a program designed to improve physicians' communication with patients,

researchers found that when oncologists participated in a workshop prior to the pre-treatment consultation, patients reported less depression compared to patients whose doctors did not receive the intervention (Rutter, Iconomou, & Quine, 1996). These results are supported by a study of the relationships between breast cancer survivors' experiences during the diagnostic consultation and their subsequent long-term psychological adjustment which found that patients who perceived their physicians as displaying good interpersonal skills during the initial consultation reported better psychological adjustment (Mager, & Andrykowski, 2002). Other studies have produced consistent results. Investigations into the relationship between cancer patient's perceptions of the quality of communication during the diagnostic consultation have suggested that patients who perceived interaction with their doctor as negative reported poorer psychological adjustment 3-4 months later (Omne-Ponten, Holmber, & Sjoden, 1994; Butow et al, 1996).

Overall, results from these studies highlight the importance of the affective quality of the doctor-patient communication in relation to patient satisfaction and affective experience during the consultation. Studies have also examined the relationship between doctor-patient communication and patients' quality of life. Results, however, suggest that the findings for adjustment do not extend to quality of life. For example, in a study of cancer patients, who were followed for 12 months after diagnosis, findings revealed that doctors communication of information to the patients in a pre-treatment consultation, did not reliably predict patients quality of life 7 weeks after the consultation (Rutter, Iconomou, & Quine, 1996). Similarly, another study examining the relationship between patients' quality of life and the nature of the doctor-patient communication found that

oncologists' behaviors were unrelated to patients' quality of life (Ong, Visser, Lammes, & de Haes, 2000).

Next follows a discussion of the second component of doctor-patient communication.

Instrumental Information

The second component of doctor-patient communication is clarity. There are two aspects to clarity of communication between doctors and patients; patients' understanding and recall of the information given, and patients' desire for the kinds of information given.

The primary goal of medical consultations in the context of cancer, and in general, is to help the patient gain an understanding of their diagnosis, prognosis, and treatment options. However, data suggests that a substantial number of cancer patients do not fully comprehend the provided medial information. In a study of 100 cancer patients, Mackillip et al (1988) found that 33% of those with metastatic disease thought their illness was localized and that 34% of those being treated palliatively believed they would be cured. These results have been supported in more recent studies. For example, in a study of how patients perceive information conveyed by their physicians (Chan & Woodruff, 1997), results indicated that nearly 10% of patients were unaware that they had a diagnosis of cancer. Upon further questioning, it became clear that one third of the patients, who had an incomplete understanding of their prognosis, overestimated their understanding of their actual prognosis. Similar findings emerged from another study investigating communication differences between physicians and their patients in an oncology setting (Sher, Cella, Leslie, Bonomi, Taylor, & Serafian, 1997). Here

researchers found that while physicians and patients disagreed on the valence of the information that was communicated, findings indicated that it were the patients who distorted the messages in a positive direction. However, it should be considered that the psychological impact of being given a cancer diagnosis might interfere with patients' ability to pay attention to other information provided during the consultation. This factor may also be linked to patient recall of information.

In a study investigating the kinds of information patients wanted from their physicians Kaplowitz, Campo, and Chiu (2002) found, in a mail survey of cancer patients, that about 80% of patients wanted a qualitative prognosis (i.e., will I die from the disease?), whereas only 50% wanted on a quantitative prognosis (i.e., how long will I survive?). Results of this study also indicated that while 90% of those who wanted a qualitative prognosis were given one, only half of those who wanted a quantitative prognosis were given one. Further, among those who had wanted a qualitative prognosis only 15% failed to ask for it, whereas more than 30% of those who wanted a quantitative prognosis failed to ask for it. Finally analyses also suggested that patients who had greater anxiety, a bad prognosis, and who needed to avoid thinking about death wanted, requested, and received significantly less information**.** Similarly, in an investigation of the doctor-patient interaction that compared patients' information about their illness and their desire for information before and after consultations with their doctor, results suggested that a majority of patients did not feel they gained any significant additional information (Chaitchik et al, 1992).

Another important aspect of the doctor-patient communication is the experience of the doctors themselves. Many doctors have reported their own difficulty and distress in

disclosing a cancer diagnoses to their patients leading them to present information in a hurried and uncaring manner due to their own discomfort, rather than a lack of respect and empathy for their patients (Ellis, & Tattersall, 1999).

Communication and Adherence

Results from research on doctor-patient communication in the context of cancer have underlined the importance of the health care provider and patient communication on patients' satisfaction with the information they have received. If one assumes that satisfaction with information provided may be linked with a deeper understanding of one's treatment, then these results implies that in-depth and repeated communication with health care providers about medical issues and treatment is integral to patients' understanding of their illness and treatment options. However, only few studies have sought to investigate the relationship between doctor-patient communication and treatment compliance despite the overwhelming finding that variables related directly to a patient's relationship with their physician along with physician recommendations are among the foremost predictors of adherence to cancer *screening* procedures. In a study examining the profile of patients who refused chemotherapy (Gilbar, 1989) results suggested that patients who had low confidence in their physicians exhibited higher rates of non-adherence as did those who had only little information about their illness. In another study by Henman et al (2002) on factors influencing treatment decision making among women with breast cancer, findings suggested that while women cited the risk of recurrence, life expectancy, side-effects, and quality of life as influencing their decisions, they placed at least as much emphasis on their personal relationship with the specialist.

The specific physician characteristic that emerged as predictors of acceptance of primary treatment recommendations were; caring, understanding, respecting the patients and being perceived as trustworthy, open and honest.

In summary, the patients' perceptions of the affective quality of their interactions with doctors has been associated with patients' satisfaction with the consultation and psychological adjustment. With respect to instrumental information there appears to be a discrepancy between what doctors feel they have communicated and what patients report recalling with patients having a tendency to distort information in the positive direction. In addition, the desire for information varies widely among cancer patients. Research on the relationship between doctor-patient communication and treatment adherence indicate that the physician's behavior during the diagnostic consultation as well as patients' confidence in their physician may predict subsequent treatment adherence.

Coping

Receiving a diagnosis of cancer is a shocking and traumatic event; patients have to digest this new information along with a number of social, prognostic, and treatment related implications. Research has suggested that cancer patients' coping strategies are associated with their psychological adjustment to their illness.

Several studies have investigated the link between specific coping strategies and adjustment among cancer patients. In studies of breast cancer patients results suggested that the use of emotion-focused coping, which included ventilation and avoidance strategies, was related to increased distress and poor adjustment (Ben-Zur, Gilbar, & Lev, 2001; McCaul, Sandgren, King, O'Donnell, Branstetter, & Foreman, 1999). Further, the

choice of coping strategy has been linked to subjective reports of physical and psychological side effects during treatment with adjuvant chemotherapy among women with breast cancer (Spairo, Boggs, Rodrigue, Urry et al, 1997). Specifically, the authors found that women, who exhibited coping strategies characterized by engagement in understanding their illness and taking part in the medical decision progress, reported significantly fewer psychological and physical symptoms than those endorsing the use of avoidant coping strategies, suggesting that willingness to talk and think about the illness may be an important component in how side effects of treatment are experienced.

Other studies support the notion that a passive patient role is associated with poorer adaptation to illness than a more active role and emphasize the importance of promoting positive-focus coping strategies among patients (Cohen, 2002; Arraras, Wright, Jusue, Tejedor, & Calvo, 2002). Further, women who take an active role, defined as the employment of coping strategies aimed at problem solving, the expression of emotion, and restructuring one's lifestyle, while undergoing diagnosis and treatment report better quality of life (Royak-Schaler, 1991). In a study examining the effects of hope and coping strategies on adjustment to the diagnosis of cancer (Stanton, Danoff-Burg, & Huggins, 1991), results suggested that patients who accepted their diagnosis and who used a low rate of avoidant coping reported better psychological adjustment to their illness one year post diagnosis.

Another study of cancer patients' coping styles and doctor-patient communication (Ong, Visser, Van Zuuren, Rietbroek, Lammes, & de Haes, 1999) examined the relationship between coping style and patients' preferences for information and participation in decision-making, the relationship between monitoring and blunting

coping styles and prognosis, and the relationship between patients' coping styles and communicative behaviors and global affect during the initial oncological consultation. Results of the studies found that a monitoring coping style was linked to preference for more detailed information and increased participation in medical decision-making. Further, a monitoring coping style was also positively associated with patients' question asking and dominance during the consultation. Similar results emerged from a study examining attitudes of cancer patients (Keltikangas-Jaervinen, 1986). Findings revealed that patients who experienced their illness as a loss and who felt rational sorrow over lost health were more active in their own treatment and more likely to comply with treatment, whereas those who experienced their illness as a threat or challenge exhibited passive engagement in treatment decisions.

Overall, research suggests that patients, who employ coping styles that can be characterized by involvement in medical decision making and a desire to understand and gain information about their illness, tend to better adjusted than those who do not, and are more likely to be proactive in their interactions with physicians.

Illness Perceptions

The cancer screening literature has suggested that major components in people' decision to go through with cancer screening recommendations are knowledge about cancer and cancer screening as well as personal beliefs about the nature of the screening procedure and the usefulness of screening. Research in the area of cancer treatment adherence has indicated that these factors may also play a role in patients' decisions to adhere to treatment. The specific components of patients' illness perceptions that were

examined in this study pertains to beliefs about a) risks of complications and relapse, b) consequences of not adhering to recommended treatment, c) the benefits of adhering to recommendations, d) efficacy of treatment, and e) perceived barriers to adherence.

Patients' illness perceptions have been suggested as essential in creating the cognitive and psychological framework within which patients make treatment decision (Buick, 1997), and a series of studies have attempted to link patients' illness-related cognitions to treatment adherence. In a study exploring factors that influence medical information seeking and treatment engagement among cancer patients, results revealed that limited knowledge and misinformation about cancer were linked to poor adherence to health related behaviors among cancer patients (Matthews, Sellergren, Manfredi, & Williams, 2002).

Patients' beliefs about cancer treatment have also been associated with treatment adherence. For example, patients who believed that side effects of treatment would be likely and severe were significantly more likely to be non-compliant (Siminoff & Fetting (1991) as were patients who reported low expectations of the treatment outcome (Gilbar, 1989). Another study examined adherence to oral medication regimens among adolescent and young adult cancer patients (Tamaroff, Festa, Adesman, & Walco, 1992). Results revealed no effects of treatment variables, such as treatment duration, continuity, or complexity. However, patients who adhered poorly to the therapeutic regimen had significantly less developed concepts of the illness (specifically, concepts of causality and prognosis), less perceived vulnerability, and higher levels of denial. Horne & Weinman (1999) conducted a study of patients' personal beliefs about the necessity of their prescribed medication and their concerns about taking it among patients with chronic

illness. The relationship between beliefs and reported adherence were examined and results indicated that beliefs about medicines were related to reported adherence. Specifically, high necessity scores with respect to the benefit of the medication were related to high adherence whereas a high number of concerns about the medication were correlated with lower reported adherence. The lowest adherence was observed among patients whose concerns exceeded the perceived necessity of medication.

Other evidence for the link between patients' illness perceptions and treatment adherence is circumstantial and has been derived indirectly by examining the influence of patients' beliefs about cancer on psychological adjustment, which has been linked with treatment adherence. Such studies have examined cognitions about cancer paying specific attention to patients' emotional reaction to diagnosis and concerns about the treatment process, as well as the impact on patients' sense of identity, interpersonal relationships, and beliefs about the future (Fife, 1995; Browne et al, 1988). Results have suggested that having a positive attitude, characterized by optimism, having few irrational beliefs, and endorsement of internal goals, rather than external goals, predicts personal control and psychological adjustment to the illness (Fife, 1995; Arman, et al, 2001; Vickberg, et al, 2001; Thompson & Pitts, 1993).

Generally, research examining the effect of patients' beliefs about their illness and treatment has suggested that there may be a link to treatment adherence. Results from this research have suggested that the following components of illness perceptions may all be predictors of low treatment adherence: lack of knowledge about cancer and cancer treatment; beliefs about side effects; low expectations of treatment efficacy; poor

understanding of causality, prognosis, and vulnerability; and a high cost/benefit ratio of treatment.

Hypotheses

The following hypotheses were proposed:

Hypotheses relating to doctor-patient communication

1. It was hypothesized that there would be a positive relationship between the patients' perception of the affective quality of the doctor-patient communication, at baseline, and

   a. intent to adhere at baseline
   b. adherence to the recommended oral care regimen (post-treatment and follow-up)
   c. cessation of tobacco use (post-treatment and follow-up)
   d. alcohol abstinence (post-treatment and follow-up)
   e. patients' illness perceptions (baseline, post-treatment, and follow-up)

2. It was hypothesized that there would be a positive relationship between patients' perception of the instrumental/informative quality of the doctor-patient communication, at baseline, and

   a. intent to adhere at baseline
   b. adherence to the recommended oral care regimen (post-treatment and follow-up)
   c. cessation of tobacco use (post-treatment and follow-up)
   d. alcohol abstinence (post-treatment and follow-up)
   e. patients' illness perceptions (baseline, post-treatment, and follow-up)

Hypotheses pertaining to patient coping

3. It was hypothesized that there would be a positive relationship between patients' adaptive coping and

a. intent to adhere at baseline
b. adherence to the recommended oral care regimen (post-treatment and follow-up)
c. cessation of tobacco use (post-treatment and follow-up)
d. alcohol abstinence (post-treatment and follow-up)
e. patients' illness perceptions (baseline, post-treatment, and follow-up)

4. It was hypothesized that there would be a negative relationship between patients' maladaptive coping and

a. intent to adhere at baseline
b. adherence to the recommended oral care regimen (post-treatment and follow-up)
c. cessation of tobacco use (post-treatment and follow-up)
d. alcohol abstinence (post-treatment and follow-up)
e. patients' illness perceptions (baseline, post-treatment, and follow-up)

Hypotheses related to illness perceptions

5. It was hypothesized that patient's illness related perceptions would be positively related to

a. intent to adhere at baseline
b. adherence to the recommended oral care regimen (post-treatment and follow-up)
c. cessation of tobacco use (post-treatment and follow-up)
d. alcohol abstinence (post-treatment and follow-up)

Hypotheses related to intent to adhere

6. With regard to the predictive value of baseline intent to adhere on actual adherence at follow-up, it was hypothesized that baseline intent to adhere with doctors recommendations would be positively related to actual adherence to

a. the recommended oral care regimen (post-treatment and follow-up)
b. cessation of tobacco use (post-treatment and follow-up)
c. alcohol abstinence (post-treatment and follow-up)

Mediation hypotheses

7. It was hypothesized that patients' illness perceptions would emerge as a partial mediator of the relationship between patients' perceptions of the affective quality of the doctor-patient communication, at baseline, and

a. adherence to the recommended oral care regimen (post-treatment and follow-up)
b. cessation of tobacco use (post-treatment and follow-up)
c. alcohol abstinence (post-treatment and follow-up)

8. Similarly, it was hypothesized that patients' illness perceptions would emerge as a partial mediator of the relationship between patients' perceptions of the instrumental/informative quality of the doctor-patient communication and

a. adherence to the recommended oral care regimen (post-treatment and follow-up)
b. cessation of tobacco use (post-treatment and follow-up)
c. alcohol abstinence (post-treatment and follow-up)

Moderation hypotheses

9. It was hypothesized that patients' coping would moderate the relationship between patients' perceptions of the affective quality of the doctor-patient communication, at baseline, and

a. adherence to the recommended oral care regimen (post-treatment and follow-up)
b. cessation of tobacco use (post-treatment and follow-up)
c. alcohol abstinence (post-treatment and follow-up)

10. Similarly, it was hypothesized that patients' coping would moderate the relationship between patients' perceptions of the instrumental/informative quality of the doctor-patient communication, at baseline, and

a. adherence to the recommended oral care regimen (post-treatment and follow-up)
b. cessation of tobacco use (post-treatment and follow-up)
c. alcohol abstinence (post-treatment and follow-up)

Exploratory questions

Exploratory analyses examined the moderating effects of depression, cancer site, stage of illness, treatment modality, and oral functioning on the relationships between

a. patients' perceptions of doctor-patient communication and patient adherence
b. patients' illness perceptions and patient adherence
c. patients' coping and patient adherence

CHAPTER 4: RESEARCH DESIGN AND METHODS

Design

This is a longitudinal study examining adherence to an oral hygiene regimen, tobacco cessation, and alcohol abstinence among patients with oral or oralpharyngeal cancer. One hundred and ten patients scheduled for radiation therapy at the University of Texas MD Anderson Cancer Center (UTMDACC) were enrolled in the study. Utilizing self-administered questionnaires, baseline assessments of all independent variables in the proposed model were made after the initial consultation with the dental oncologist. All patients were contacted for a follow up evaluation of baseline measures in addition to subjective measures of adherence to the recommended treatment regimen immediately after the end of treatment and again 3 months later.

Eligibility

Participants were solicited through the UTMDACC head and neck cancer radiation clinic. Patients with oral cavity or oralpharyngeal cancers who were scheduled to receive radiation therapy to the oral cavity or the lower part of the face were eligible for the study. Two restrictions applied: only patients who were oriented to person, place, and time were included in the study as previous research has indicated that severe psychiatric illness often hinders a patient's ability respond to questionnaires as well as negatively impact their ability to adhere to medical recommendations (Kunkel, Woods, Rodgers, & Myers, 1997). Secondly, due to the specific aim of this study, to investigate adherence to a strict oral care regimen, only dentulous patients were selected for participation in the study.

Procedures

One hundred and twenty six patients were approached for participation in the study. Eight declined participation due to feeling too ill, already being part of other studies and feeling one more study would be too much, or stated they were not interested with no further explanation. Attrition equaled 9.3% with 4 patients dying before completing the study and 7 patients dropping out due to feeling ill or too overwhelmed.

Patients were enrolled in the study post diagnosis but prior to radiation treatment. All patients underwent an extensive dental exam and evaluation performed by a dental oncologist to assess baseline oral health status. Upon conclusion of the dental consultation, but prior to radiation therapy, all patients were offered the opportunity to participate in the study. If a patient expressed interest in participating, a brief interview followed during which eligibility was determined. If the patient was eligible, the consent form and the purpose of the study were discussed. Patients who chose to participate were asked to fill out a series of questionnaire at baseline assessing: Demographic variables, medical history including baseline oral care practices, perceptions of the quality of doctor-patient communication, illness perceptions, intentions of adhering, baseline oral functioning, coping, and depression.

The treatment phase with radiation for head and neck cancer typically lasts from 5 to 8 weeks depending on stage and location of the cancer. Within one week of the end of treatment all patients were contacted for a follow up evaluation of: self-reported adherence to oral care regimen, smoking cessation and alcohol abstinence; illness perceptions; oral functioning; and depression. This evaluation was repeated at a second follow-up 3 months post-treatment.

Measures

Background Information

Demographic Variables

Demographic information was collected including: date of birth, current age, ethnic background, marital status, employment status, level of education, and annual household income.

Variables Pertaining to Medical History

Medical history was collected by chart review. This information included general medical history such as 1) the presence and treatment of non-cancer medical conditions, 2) family history of cancer, 3) previous history of cancer and medical information pertaining to the current cancer diagnosis: 1) the site of the cancer, 2) the stage of the cancer, and 3) the recommended treatment plan (surgery and radiation vs. radiation alone).

Other medical information was obtained through questionnaire: 1) smoking status, 2) alcohol use, and frequency of 3) brushing, 4) flossing, and 5) dental exams.

Control Variables

Oral Functioning

Oral functioning was assessed to measure the extent to which cancer and cancer treatment has impacted patients' ability to perform normal activities involving the physical structures of the neck and oral cavity. Head and neck cancer patients often

experience impairments in their ability to chew, swallow, breathe normally, and communicate verbally.

Oral functioning was assessed using the Head and Neck Cancer Subscale of the Functional Assessment of Cancer Therapy-Head and Neck Scale, FACT-H&N (List et al, 1996). The FACT-H&N consists of a core scale FACT-General (FACT-G) in addition to a Head and Neck Cancer Subscale (NHCS). The FACT-G is a multidimensional Quality of Life instrument developed by Cella et al (1993). This instrument has been specifically designed to be used among cancer patients. Only the HNCS will be used in this study. The HNCS assesses the specific functional impact of head and neck cancer. The scale consists of 9 items tapping oral functioning, which are scored on a 5-point Likert scale and summed for a total score. The measure has an internal consistency of $\alpha = .63$ (List et al, 1996).

Mental Status

Mental status was assessed at baseline using a checklist of the Mental Status Examination (MSE). The MSE has a long history of use for obtaining information about a patient's level of functioning and self-presentation ( ). The MSE assesses functioning in four categories: appearance and general behavior, interview behavior, thought, and cognitive functioning.

Depression

Given the high prevalence of depression among medical patients, including cancer patients, depression will be assessed at each time point using the Center for Epidemiologic Studies – Depression Scale (CES-D) (Radloff, 1977). The CES-D Scale is

a short, and widely used, self-report scale designed to measure depressive symptoms in the general population and has been examined for use specifically in the head and neck cancer population (Katz et al, 2004). The measure has good internal consistency, alpha = .80, and has been well validated. It was chosen over other measures of depression due to is relative low number of items tapping physical signs of depression, such as fatigue, that might be confused with the physiological correlates of cancer and cancer treatment. The measure consists of 20 items scored on a 4-point scale, with higher scores reflecting more severe depressive pathology. Items are summed to arrive at a conclusive score.

Independent Measures

Doctor-Patient Communication

In this study doctor-patient communication refers to the interaction the patient has with his or her dental oncologist. Patient perceptions of doctor-patient communication include two aspects. The first aspect concerns the patient's perception of the quality of the information received during the consultation, i.e. is the information communicated in a manner that the patient can understand, does the doctor answer questions, does the patient feel that enough information has been given, and is the information appropriate to the patients specific circumstance. The second aspect of communication that was examined is concerned with the patients' experience of affective nature of the consultation, does the doctor express appropriate affect, is he/she experienced as supportive and caring, and is the doctor able to tolerate patient affect. Finally, there is the socio-emotional aspect of the consultation, which is concerned with non-verbal behaviors that express caring and a focus on the patient, i.e. does the doctor take time to talk with the patient or is he/she

experienced as being in a rush, and does the doctor sit down while talking to the patient. Patients' perceptions of the instrumental, affective, and socio-emotional qualities of the consultation was assessed using the Cancer Diagnostic Interview Scale, CDIS (Roberts, Cox, Reintgen, Baile, & Gibertine, 1994). The CDIS assesses patients' perceptions of their doctor's communication in the three areas described above. The CDIS consists of 20 items scored on a 5-point Likert scale. The CDIS has an internal consistency of .92.

Coping

Patient's coping strategies was assessed using the dispositional version of the brief COPE (Carver, 1997; Carver, & Scheier, 1994). The COPE is a multidimensional coping inventory which assesses response to stress in several different areas (Carver, Scheier, & Weintraub, 989). The Brief COPE is an abbreviated version of the COPE, consisting of two items from each of the 12 original subscales resulting in 24, items, which are scored on a 4-point Likert scale. Each scale can be categorized as depicting either adaptive or maladaptive coping. The scales have good internal consistency ranging from .45 to .92.

Illness Perceptions

Patients' illness perceptions were assessed using the Adherence Determination Questionnaire (ADQ) (DiMatteo, et al, 1993). The ADQ is a measure designed to identify predictors of treatment adherence. The ADQ consist of 7 subscales assessing: perceived utility of treatment, perceived severity of illness, perceived susceptibility to illness, future intentions of adhering, perception of barriers to adhering, interpersonal aspects of care and subjective norms. The latter two subscales were not included in this study. Internal consistencies for the five subscales included in the study are as follows:

perceived utility of treatment (α = .76), perceived severity of illness (α = .65), perceived susceptibility to illness (α = .69), future intentions of adhering (α = .84), and perception of barriers to adhering (α = .65).

Another aspect of patients' illness perceptions that was assessed is concerned with patients' beliefs about the causes of their illness. The Illness Perceptions Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris, & Horne, 1996) is a valid instrument, consisting of five scales, which assesses patients' cognitive representations of illness. Each scale can be measured and scored independently. The causal component scale, which will be used in this study, comprises patients' personal ideas about etiology. The scale consists of 12 items. The authors have deemed it inappropriate to sum all of the items as each represent a specific causal beliefs. For the purposes of this study, however, items will be combined into two categories assessing internal versus external causes.

Dependent Measures - Adherence

Adherence will be measured in three different areas: adherence to an oral care regimen, tobacco use, and alcohol consumption. Tobacco and alcohol use were assessed using items from the Behavioral Risk Factor Surveillance System (BRFSS) developed by the Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, 1999). In the analyses tobacco use was operationalized as the average number of cigarettes smoked a day over the past 2 weeks. Alcohol use was operationalized at the number of alcoholic drinks at patient had had over the past month. Eight self-report items asking patients about frequency of tooth brushing, flossing, dental visits and other dental care at baseline. There was no existing measure for adherence to

oral care. A measure consisting of 12 face valid items was created assessing tooth brushing, flossing, fluoride application, and use of mouth rinse at each follow-up data point. Each item was scored so that a higher score reflected behavior that was closer to the recommendations made by the dental oncologist. Items were then summed to produce a single score for oral care at each time point. Internal consistent was moderate. Alpha = .50 at post-treatment and .51 at follow-up. Though assessment of the patient's oral health was also to be done objectively at the end of treatment by a dental oncologist, the logistics of getting patients back to the dentist at the time of each assessment and getting each dentist to gather the required information was beyond the scope of this study.

A broad assessment of patients' adherence to their doctor's recommendations were also obtained through the General Adherence Scale (GAS) (DiMatteo, Hays, & Sherbourne, 1992). The GAS is a five-item scale assessing patients' consistency in following through with medical recommendations. The GAS has been validated in several illness populations, including the head and neck cancer population, and internal consistency has been reported to be .66 or higher (DiMatteo, Hays, & Sherbourne, 1992).

Analyses

Descriptive Statistics

Descriptive analyses compiling means and standard deviations for the major study variables were computed. Zero-order correlations were also calculated among study variables.

Predictive Analyses

The shared and unique predictive variance of each independent variable (patients' perceptions of doctor-patient communication, patients' illness perceptions, and patients' dispositional coping) with the dependent variable, patient adherence (measured as 1. adherence to the recommended oral care regimen, 2. cessation of tobacco use, and 3. alcohol abstinence) was examined using linear regression analyses at each time point.

Mediation Analyses

It was hypothesized that patients' illness perceptions would operate as a partial mediator of the relationship between patients' perceptions of both aspects of the doctor-patient communication at baseline and adherence.

Linear regression analyses were conducted between the independent variable and dependent variable, and between the independent variable and the proposed mediator to determine whether the relationships were appropriate (i.e. were significant) for mediational analysis. If these paths were significant, the mediational model was examined with path analysis applying Baron and Kenny's (1986) criteria for mediation, which states that mediation can be inferred when the regression of the dependent variable on the independent variable becomes non-significant (indicating full mediation) when the mediator is entered into the regression model or at the least become weaker (indicating partial mediation).

Moderation Analyses

Patients' adaptive coping was hypothesized to strengthen the relationship between both aspects of the doctor-patient communication (affective quality and instrumental information) and patient adherence.

Linear regression analyses were conducted to ensure that moderational analysis is appropriate. According to Baron and Kenny (1986) it is preferable that the moderator be uncorrelated with the independent variable and the dependent variable or, at the very least, that these relationships are weak. Using the criteria set forth by Baron and Kenny, the independent variable and the moderator will both entered in block 1 of a regression model and the interaction term will be entered in block 2. According to Baron and Kenny (1986) moderation by the proposed moderator may be inferred if the interaction term produces a significant result. If the interaction term was significant, the hypothesized model was examined separately at low and high (median split) levels of adaptive coping.

CHAPTER 5: RESULTS

Demographics

The sample consisted of 107 patients diagnosed with head and neck cancer. All patients were treated at MDACC. The sample was primarily male: 73.2% versus 26.8% female. Age ranged from 32 to 76 years old. The mean age was 55. The sample was overwhelmingly Caucasian, 90.7%, with 3.1% African Americans, 3.1% Asian, 1% Native American, and 2.1% Hispanic patients. Most patients were married, 80.4%, with 6.2% indicating that they had never married, 9.3% indicating divorce or separation, 2.1% indicating that they were widowed, and 2.1% indicating "other" marital status. Sixty percent of the sample was employed full time, 4.2% were unemployed, 6.3% worked within the home, 22.1% were retired, and 6.3% were disabled. The sample was well educated with 27.1% have completed some college, 30.2% having graduated college, and 20.8% having postgraduate education or degrees. Seventeen percent had a high school diploma, and only 4.2% did not graduate high school. Income was above average as well with 68% reporting an income of $50.000 or more a year.

Illness Characteristics

Among patients in the current sample 26.4% had a previous diagnosis of cancer. Head and neck cancer had been present in 52% of these cases. Sixty seven percent of patients had a family history of cancer. The sites of current cancer were distributed as follows: 27.9% had oral cancer, 67.6% had oralpharyngeal cancer, and 4.4% had cancers at other head and neck sites. Treatment varied from radiation only, 22%, to concurrent chemo-radiation, 16.7%, and surgery followed by radiation, 38.9%. Of those receiving

chemotherapy most received 3 cycles. The mode for radiation treatment was 30 treatments spaced over a 6-week period.

Adherence Rates

At baseline 80.9% of the sample reported brushing their teeth daily, and of those 60% reported brushing twice a day or more often. Thirty-one percent reported that they flossed daily and among those who did, 54% reported that they flossed at least once a day. However, 80% of the sample had not been to see a dentist or have their teeth cleaned for more than 5 years. With respect to tobacco and alcohol use, data revealed that at baseline only 6% smoked on a daily basis, 1.8% used smokeless tobacco, and 38% revealed some use of alcohol over the past month. It should be noted though that between 40 – 70% of the sample had missing data for these three variables.

At post-treatment 46% reported brushing their teeth daily. Approximately 50% of the sample had no data for oral care at post-treatment. Of those who did brush daily, 95% reported brushing at least twice a day. This is up by almost 40% from baseline. The rate of flossing went down to 23% reporting daily flossing, and among those 28% flossed more than once a day. At the end of radiation treatment, when oral discomfort is likely the worst, 30 % of the sample reported using fluoride daily as instructed. A higher number, 45 %, reported using the baking soda rinsing solution. Interestingly, data revealed a higher rate of cigarette use at post-treatment, with 25 % of the sample indicating that they smoked 1 cigarette a day. Only one patient reported using smokeless tobacco at post-treatment. Alcohol use was down significantly from baseline with only 4% of the sample reporting any use of alcohol over the past month. As was the case at

baseline, a high number of patients had some missing data with respect to the three outcome variables: Oral care, tobacco use, and alcohol use.

Among the data that was collected at follow-up 39 % of patients reported daily brushing, and among those 75 % brushed at least twice a day. However, only 17 % of the sample reported flossing their teeth daily at follow-up, and among those who did 30% flossed more than once a day. Use of fluoride was a disappointing 18 %, and use of baking soda rinse had dropped to 20%. Approximately 13% of those who had data available at follow-up reported daily use of cigarettes, no one reported using smokeless tobacco, and 12% reported alcohol use within the past month. However, many patients had at least some data missing from the three outcome measures.

Descriptive Statistics and Predictive Analyses

Descriptive analyses compiling means and standard deviations for the major study variables were computed (tables 1 - 4). Zero-order correlations were also computed between all major variables in the model. They are reported below for each hypothesis. See also tables 5- 54. The shared and unique predictive variance of each independent variable (patients' perceptions of doctor-patient communication, patients' illness perceptions, and patients' dispositional coping) with the dependent variable, patient adherence, measured as 1) adherence to the recommended oral care regimen, 2) cessation of tobacco use, 3) alcohol abstinence, and 4) overall self-reported adherence, was examined using linear regression analyses, controlling for the baseline value of each dependent variable, at each time point. Results are reported below for each hypothesis.

	N	Missing	Minimum	Maximum	Mean	Std. Deviation
Instrumental information	86	21	10.00	40.00	25.337	5.005
Socio-emotional behavior	88	19	13.00	30.00	25.034	4.066
Affective quality	83		8.00	30.00	13.373	4.053
Baseline avoidant coping	90	17	13.00	33.00	21.050	4.217
Baseline approach coping	90	17	23.00	47.00	36.977	5.662
External causes	92	15	11.00	31.00	19.619	4.989
Internal causes	94	13	9.00	33.00	18.010	6.181
Baseline utility subscale	92	15	12.00	40.00	24.597	4.552
Baseline severity subscale	89	18	4.00	14.00	8.842	2.158
Baseline susceptability subscale	91	16	4.00	16.00	10.472	2.895
Baseline barriers subscale	93	14	4.00	16.00	11.860	2.282
Baseline intentions subscale	91	16	10.00	20.00	12.505	2.213
oral care at baseline	97	10	7.00	30.00	21.154	4.826
Cigarettes per day	70	37	.00	30.00	1.428	5.417
Smokeless tobacco use	2	105	1.00	1.00	1.000	.000
Monthly alcohol use	42	65	.00	70.00	17.702	20.332

Table 1: Baseline table with means and standard deviations for each major variable in the model.

	N	Missing	Min	Max	Mean	Std. Deviation
T2 utility subscale	60	47	24.00	40.00	37.300	3.907
T2 severity subscale	55	52	10.00	18.00	13.509	2.053
T2 susceptability subscale	59	48	6.00	18.00	12.016	2.603
T2 barriers subscale	60	47	11.00	20.00	16.900	2.588
T2 intentions to adhere	60	47	13.00	20.00	19.133	1.630
Oral care	40	67	27.00	45.00	36.550	4.030
No of Cigarettes a day	32	75	.00	30.00	1.750	5.168
Smokeless tobacco	1	106	1.00	1.00	1.000	a
Monthly alcohol use	10	97	.00	62.50	15.050	24.210
Self-reported Adherence	56	51	5.00	28.00	17.419	4.415

Table 2: Post-treatment table with means and standard deviations for each major variable in the model.

a. Cannot be computed because at least one of the variables is a constant.

	N	Missing	Min	Max	Mean	Std. Deviation
T3 utility subscale	44	63	16.00	26.00	23.568	1.809
T3 severity subscale	45	62	4.00	12.00	9.200	1.914
T3 susceptability subscale	45	62	4.00	14.00	10.088	2.618
T3 barriers subscale	45	62	10.00	16.00	12.733	1.543
T3 intentions to adhere	45	62	8.00	14.00	11.711	.869
Oral care	17	90	22.33	44.00	34.705	4.851
Cigarettes per day	15	92	1.00	1.00	1.000	0.000
Smokeless tobacco	0	107	a	a	a	a
Monthly use of alcohol	18	89	.00	24.00	7.000	7.259
Self-reported Adherence	44	63	4.00	17.00	12.568	2.084

Table 3: Follow-up table with means and standard deviations for each major variable in the model.

a. Cannot be computed because at least one of the variables is a constant.

	N	Missing	Min	Max	Mean	Std. Deviation
Baseline CESD	88	19	.00	45.00	8.670	9.468
Post-Treatment CESD	53	54	1.00	47.00	13.000	9.575
Follow-Up CESD	45	62	.00	52.00	9.644	12.227
Baseline FACTHN	86	21	24.00	36.00	30.983	3.609
Post-Treatment FACTHN	51	56	19.00	36.00	29.941	3.036
Follow-Up FACTHN	45	62	25.00	35.00	30.578	2.554

Table 4: Means and Standard deviations of Depression at each time point and functional status at each time point.

Hypotheses Relating to Doctor-Patient Communication

It was expected that there would be a positive relationship between the three aspects patients' perception of the doctor-patient communication at baseline (instrumental information, socio-emotional, and affective quality), and intent to adhere (baseline, post-treatment, and follow-up) as well as adherence to the recommended oral care regimen (post-treatment and follow-up). A negative correlation was predicted between doctor-patient communication and cessation of tobacco use (post-treatment and follow-up) as well as between doctor-patient communication and alcohol abstinence (post-treatment and follow-up). A positive correlation was predicted for doctor-patient communication and oral care as well as self-reported adherence (post-treatment and follow-up). It was hypothesized that patients' illness perceptions (baseline, post-treatment, and follow-up), would relate to doctor-patient communication as follows: it was predicted that there would be a positive relationship between beliefs about the utility of treatment, but a negative relationship between doctor-patient communication and beliefs about severity, susceptibility, and barriers to adherence.

Socio-Emotional Behavior

It had been predicted that there would be a positive relationship between the patients' perception of the socio-emotional behavior displayed by the doctor, at baseline, and intent to adhere (post-treatment and follow-up) and oral care (post-treatment and follow-up). It was expected that there would be a negative relationship between the socio-emotional behavior displayed by the doctor and tobacco use (post-treatment and follow-up) and alcohol use (post-treatment and follow-up). Analyses were also performed to examine the

relationship between patients' perception of the socio-emotional behavior displayed by the doctor and patients' illness perceptions at each time point. See tables 5-13, page 100. Analyses produced the following results.

a. As expected intent to adhere at baseline was positively related to the socio-emotional behavior of the doctor. There was a significant correlation between the socio-emotional quality of doctor-patient communication at baseline and intent to adhere at baseline ($r = .225$, $p < 0.05$). However, this finding did not extend to other time points.

b. It was hypothesized that there would be a positive relationship between the patients' perception of the socio-emotional behavior displayed by the doctor and the patient's later adherence to the recommended oral care regimen (post-treatment and follow-up). There were no significant correlations or regressions found at any time point for oral care and the socio-emotional behavior of the doctor.

c. It was predicted that there would be a negative relationship between the patients' perceptions of the socio-emotional behavior displayed by the doctor and tobacco use (post-treatment and follow-up). There were no significant correlations or regressions found for tobacco use and socio-emotional behavior of the doctor at any time point.

d. It had been expected that there would be a negative relationship between the patients' perception of the socio-emotional behavior displayed by the doctor and alcohol use (post-treatment and follow-up). There were no significant correlations

or regressions found for alcohol use care and socio-emotional behavior of the doctor.

e. Correlation analyses between the patients' perception of the socio-emotional behavior displayed by the doctor and illness perceptions produced the following results: There was a negative correlation between socio-emotional behavior and baseline beliefs about the severity of illness ($r = -.263$, $p < 0.05$) and baseline beliefs about barriers to adherence ($r = -.240$, $p < 0.05$). That is, the more satisfied patients were with physician behavior, the less severe the believed the oral complications were and the fewer barriers they perceived at baseline. Socio-emotional behavior was also negatively correlated with beliefs about barriers at post-treatment ($r = -.457$, $p < 0.01$) and beliefs about susceptibility to future complications at follow-up ($r = -.394$, $p < 0.05$). Linear regressions found that physician's socio-emotional behavior was a good predictor of perceived barriers at post-treatment ($\beta = -.403$, $p < 0.01$) and beliefs about susceptibility at follow-up ($\beta = -.376$, $p < 0.01$). That is, the more satisfied patients were with physician behavior, the fewer barriers they perceived and the less susceptible they believed themselves to be to future complications.

Affective Quality

It was hypothesized that there would be a positive relationship between the patients' perception of the affective quality of the doctor-patient communication, at baseline, and intent to adhere (post-treatment and follow-up) and oral care (post-treatment and follow-up). It was expected that there would be a negative relationship between the affective

quality of the doctor-patient communication and tobacco use (post-treatment and follow-up) and alcohol use (post-treatment and follow-up). Analyses were also performed to examine the relationship between patients' perceptions of the affective quality of the doctor-patient communication and patients' illness perceptions at each time point. See tables 5-13, page 100.

a. Intent to adhere at baseline was hypothesized to be positively related to the affective quality of the doctor-patient communication. Consistent with hypotheses, there was a significant correlation between the affective quality and intent to adhere at baseline ($r = .798$, $p < 0.01$). However, no other significant correlations or regressions were found at any time point.
b. It was predicted that there would be a positive relationship between the patients' perception of the affective quality of the doctor-patient communication and adherence to the recommended oral care regimen (post-treatment and follow-up). Contrary to predictions, there were no significant correlations or regressions found for oral care and affective quality.
c. It had been expected that there would be a negative relationship between the patients' perception of the affective quality of the doctor-patient communication and tobacco use (post-treatment and follow-up). While there was a correlation between the affective quality and baseline use of cigarettes ($r = .281$, $p < 0.05$), there were no other significant correlations, nor regressions, found for either of the two downstream time points.
d. It was hypothesized that there would be a negative relationship between the affective quality of the doctor-patient communication and alcohol use (post-

treatment and follow-up). However, there were no significant correlations or regressions found for alcohol use and affective quality.

e. Correlation analyses between the patients' perception of the affective quality of the doctor-patient communication and illness perceptions produced the following results: Affective quality of the doctor-patient communication was correlated with baseline beliefs about the utility of treatment ($r = .785$, $p < 0.01$) and baseline beliefs about barriers to adherence ($r = -.604$, $p < 0.01$). That is the more satisfied patients were with the affective quality of the communication the higher their belief in the utility of treatment and the less barriers they perceived at baseline. There were no significant predictive relationships between these variables at any time point.

Instrumental Quality

It was hypothesized that there would be a positive relationship between the patients' perception of the instrumental quality of the doctor-patient communication, at baseline, and intent to adhere (post-treatment and follow-up) as well as between instrumental quality and oral care (post-treatment and follow-up). It was expected that there would be a negative relationship between the affective quality of the doctor-patient communication and tobacco use (post-treatment and follow-up) and alcohol use (post-treatment and follow-up). Analyses were also performed to examine the relationship between patients' perceptions of the instrumental quality of the doctor-patient communication and patients' illness perceptions at each time point. See tables 5-13, page 100.

a. Intent to adhere at baseline was hypothesized to be positively related to the instrumental quality of the doctor-patient communication. Consistent with hypotheses, there was a significant correlation between the instrumental quality of the doctor-patient communication and intent to adhere at baseline ($r = .602$, $p < 0.01$) and intent to adhere at follow-up ($r = .331$, $p < 0.05$). That is the more satisfied the patient was with the instrumental quality, the better the intent to adhere was at baseline and post-treatment. The relationship between instrumental quality and intent to adhere at follow-up remained significant with regression analysis controlling for baseline intent to adhere ($\beta = .352$, $p < 0.05$).

b. It was predicted that there would be a positive relationship between the patients' perception of the instrumental quality of the doctor-patient communication and adherence to the recommended oral care regimen (post-treatment and follow-up). However, there were no significant correlations or regressions found for oral care and instrumental quality.

c. It was expected that there would be a negative relationship between the instrumental quality of the doctor-patient communication and tobacco use (post-treatment and follow-up). Contrary to expectations, there were no significant correlations or regressions found for tobacco use and instrumental quality.

d. It was hypothesized that there would be a negative relationship between the instrumental quality of the doctor-patient communication and alcohol use (post-treatment and follow-up). However, there were no significant correlations or regressions found for alcohol use care and instrumental quality.

e. It was predicted that patients' illness perceptions (baseline, post-treatment, and follow-up), would relate to the instrumental quality of the doctor-patient communication as follows. There would be a positive relationship between instrumental quality and beliefs about the utility of treatment, but a negative relationship between instrumental quality and beliefs about severity, susceptibility, and barriers to adherence. As hypothesized instrumental quality was positively correlated with beliefs about the utility of treatment at baseline ($r = .526$, $p < 0.01$) and at follow-up ($r = .454$, $p < 0.01$). Consistent with hypotheses instrumental quality was negatively correlated with beliefs about barriers to adherence at baseline ($r = -.472$, $p < 0.01$) and also a post-treatment ($r = -.281$, $p < 0.05$). Regression analyses revealed that instrumental quality of the doctor-patient communication was a good predictor of beliefs about the utility of treatment at follow-up ($\beta = .453$, $p < 0.01$). That is, the more satisfied patients were with the instrumental quality the higher was their belief in the utility of the oral care regimen.

		Baseline intentions	T2 intentions	T3 intentions
CDIS instrumental	Pearson Correlation	.602**	.053	.331*
	N	83	51	41
CDIS socio-emotional	Pearson Correlation	.225*	.144	.023
	N	84	52	41
CDIS affective	Pearson Correlation	.798**	-.024	.261
	N	79	50	37

Table 5. Correlations between doctor-patient communication and intentions to adhere at baseline, post-treatment, and follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

		oral care at baseline	T2 oral care	T3 oral care
CDIS instrumental	Pearson Correlation	-.012	-.202	-.226
	N	86	34	15
CDIS socio-emotional	Pearson Correlation	.027	.143	.271
	N	88	35	15
CDIS affective	Pearson Correlation	-.106	-.081	.031
	N	83	34	14

Table 6. Correlations between doctor-patient communication and oral care at baseline, post-treatment, and follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

		baseline Cigarettes per day	T2 Cigarettes a day	T3 Cigarettes a day
CDIS instrumental	Pearson Correlation	.135	.309	a
	N	61	28	13
CDIS socio-emotional	Pearson Correlation	.011	.172	a
	N	62	29	13
CDIS affective	Pearson Correlation	.281*	.350	a
	N	61	28	13

Table 7. Correlations between doctor-patient communication and tobacco use as baseline, post-treatment, and follow-up.

a. Cannot be computed because at least one of the variables is a constant

**Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

		Baseline alcohol use	T2 alcohol use	T3 alcohol use
CDIS instrumental	Pearson Correlation	-.180	-.083	-.485
	N	38	9	15
CDIS socio-emotional	Pearson Correlation	-.185	.020	.016
	N	38	10	15
CDIS affective	Pearson Correlation	-.118	-.083	-.025
	N	36	10	14

Table 8. Correlations between doctor-patient communication and alcohol use as baseline, post-treatment, and follow-up.

**Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

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		External causes	Internal causes
CDIS instrumental	Pearson Correlation	-.012	-.136
	N	82	83
CDIS socio-emotional	Pearson Correlation	-.205	-.178
	N	83	85
CDIS affective	Pearson Correlation	.110	.046
	N	78	80

Table 9. Correlations between doctor-patient communication and beliefs about causes of current illness at baseline.

**Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

		Baseline utility	Baseline severity	Baseline susceptability	Baseline barriers
CDIS instrumental	Pearson Correlation	.526**	.048	-.062	-.472**
	N	84	81	83	85
CDIS socio-emotional	Pearson Correlation	.083	-.263*	-.180	-.240*
	N	85	82	84	86
CDIS affective	Pearson Correlation	.785**	.152	.212	-.604**
	N	80	77	79	81

Table 10. Correlations between doctor-patient communication and beliefs utility of treatment, severity of illness, susceptibility to future complications, and barriers to adherence at baseline.

**Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

		T2 utility	T2 severity	T2 susceptibility	T2 barriers
CDIS instrumental	Pearson Correlation	.101	-.048	.090	-.281*
	N	51	48	51	52
CDIS socio-emotional	Pearson Correlation	.185	.133	-.081	.183
	N	52	49	52	53
CDIS affective	Pearson Correlation	.045	-.066	.094	-.457**
	N	50	47	50	51

Table 11. Correlations between doctor-patient communication and beliefs utility of treatment, severity of illness, susceptibility to future complications, and barriers to adherence at post-treatment.

**Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

		T3 utility	T3 severity	T3 susceptibility	T3 barriers
CDIS instrumental	Pearson Correlation	.454	-.042	-.253	-.170
	N	40	41	41	41
CDIS socio-emotional	Pearson Correlation	-.111	-.281	-.394	-.285
	N	40	41	41	41
CDIS affective	Pearson Correlation	-.017	-.007	.272	.315
	N	36	37	37	37

Table 12. Correlations between doctor-patient communication and beliefs utility of treatment, severity of illness, susceptibility to future complications, and barriers to adherence at follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

		T2 self-reported adherence	T3 self-reported adherence
CDIS instrumental	Pearson Correlation	.568	.065
	N	48	41
CDIS socio-emotional	Pearson Correlation	.347	.052
	N	49	41
CDIS affective	Pearson Correlation	.389	-.004
	N	47	38

Table 13. Correlations between doctor-patient communication and self-reported adherence at post-treatment and follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Hypotheses Pertaining to Patient Coping

Adaptive Coping

It was hypothesized that there would be a positive relationship between patients' adaptive coping and the variables in the model. That is, the more adaptive coping the better the intent to adhere, the better the adherence to oral care recommendations, the less tobacco and alcohol use, and the more optimistic the illness perceptions.

a. No correlations were found at baseline between adaptive coping and intent to adhere at baseline, post-treatment, and follow-up. There was a positive correlation ($r = .310$, $p < 0.05$) between adaptive coping and intent to adhere at post-treatment. The more adaptive coping at baseline, the better the intent to adhere at post-treatment. No correlation was found between adaptive coping and intent to adhere at follow-up. See table 14. Linear regression analyses revealed no significant relationships between adaptive coping and intent to adhere at either post-treatment or follow-up.

		Baseline approach coping	Baseline intentions	T2 intentions	T3 intentions
Baseline approach coping	Pearson Correlation	1.000	.208	.310*	.036
	N	90	84	53	41
Baseline intentions	Pearson Correlation	.208	1.000	.175	-.031
	N	84	91	54	43
T2 intentions	Pearson Correlation	.310*	.175	1.000	.035
	N	53	54	60	37
T3 intentions	Pearson Correlation	.036	-.031	.035	1.000
	N	41	43	37	45

Table 14. Correlations between adaptive coping and intentions to adhere at baseline, post-treatment, and follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

b. It was hypothesized that there would be a positive relationship between oral care at baseline, post treatment, and follow-up and patients' adaptive coping. No significant relationships emerged between oral care and adaptive coping. See table 15. Linear regression analyses found no predictive relationships between adaptive coping and oral care at either downstream time point.

		Baseline approach coping	Baseline oral care	T2 ORAL CARE	T3 ORAL CARE
Baseline approach coping	Pearson Correlation	1.000	.166	.294	.451
	N	90	90	35	15
oral care at baseline	Pearson Correlation	.166	1.000	.336	.160
	N	90	97	38	17
T2 ORAL CARE	Pearson Correlation	.294	.336	1.000	.612
	N	35	38	40	14
T3 ORAL CARE	Pearson Correlation	.451	.160	.612	1.000
	N	15	17	14	17

Table 15. Correlations between adaptive coping and oral care at baseline, post-treatment, and follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

c. It was predicted that tobacco use at baseline, post-treatment, and follow-up would be negatively correlated with adaptive coping. There were no significant relationships found between adaptive coping and tobacco use at any time point. See table 16. Linear regression analyses revealed no predictive value of adaptive coping on tobacco use. (Note that N was too small for analyses at follow-up for cigarettes and at both post-treatment and follow-up for smokeless tobacco).

		Baseline No Cigarettes a day	T2 Cigarettes a day
Baseline approach coping	Pearson Correlation	.041	.247
	N	66	28

Table 16. Correlations between adaptive coping and tobacco use at baseline, post-treatment, and follow-up. Correlations for smokeless tobacco use at each time point, and cigarette use at follow-up could not be computed because at least one of the variables was a constant.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

d. It was hypothesized that there would be a negative correlation between alcohol use at baseline, post-treatment, and follow-up and adaptive coping. Again no significant relationships emerged. See table 17. Neither did linear regression analyses produce any significant predictive relationships between adaptive coping and alcohol use at either post-treatment or follow-up.

		Baseline approac coping	Baseline monthly use of alcohol	T2 monthly use of alcohol	T3 monthly use of alcohol
Baseline approach coping	Pearson Correlation	1.000	-.259	-.085	.161
	N	90	40	10	15
Baseline monthly use of alcohol	Pearson Correlation	-.259	1.000	.550	.708
	N	40	42	7	11
T2 monthly use of alcohol	Pearson Correlation	-.085	.550	1.000	.
	N	10	7	10	1
T3 monthly use of alcohol	Pearson Correlation	.161	.708	.	1.000
	N	15	11	1	18

Table 17. Correlations between adaptive coping and alcohol use at baseline, post-treatment, and follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

e. There were a number of significant correlations between adaptive coping at baseline and patients' illness perceptions at baseline, post-treatment, and follow-up. At baseline adaptive coping was positively correlated with beliefs about the causes of illness as follows: internal causes ($r = .222$, $p < 0.05$); external causes ($r = .304$, $p < 0.01$). This indicates that the more adaptive coping a patient engaged in the more possible causes he/she endorsed and the stronger the belief was in these cause regardless of whether these causes were internal or external. See table

18. Adaptive coping was negatively correlated with baseline beliefs about severity of one's illness ($r = -.455$, $p < 0.01$) and beliefs about barriers to successful adherence ($r = -.244$, $r < 0.05$). That is, the more adaptive coping, the less severe one's illness was perceived to be and the fewer barriers to adherences were expected. See table 19. There were no significant relationships between illness perceptions and adaptive coping at post-treatment (Table 20). However, adaptive coping was negatively correlated with follow-up beliefs about severity of one's illness ($r = -.426$, $p < 0.01$) and beliefs about susceptibility to future complications ($r = -.361$, $p < 0.05$). See tables 19-21. That is, the more adaptive coping at baseline, the less severe the illness is perceived to be at follow-up and the less susceptible the patients sees themselves to future complications.

		Baseline approach coping	**Baseline external causes**	**Baseline internal causes**
Baseline approach coping	Pearson Correlation	1.000	-.304**	-.222*
	N	90	86	88
Baseline external causes	Pearson Correlation	-.304**	1.000	.459**
	N	86	92	92
Baseline internal causes	Pearson Correlation	-.222*	.459**	1.000
	N	88	92	94

Table 18. Correlations between approach coping and causes of illness at baseline.
** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

		Baseline approach coping	Baseline utility subscale	Baseline severity subscale	Baseline susceptibility subscale	Baseline barriers subscale
Baseline approach coping	Pearson Correlation	1.000	.147	-.455**	-.164	-.244*
	N	90	85	82	84	86
Baseline utility subscale	Pearson Correlation	.147	1.000	.103	.064	-.659**
	N	85	92	89	91	92
Baseline severity subscale severe	Pearson Correlation	-.455**	.103	1.000	.326**	-.085
	N	82	89	89	89	89
Baseline ADQ susceptibility subscale	Pearson Correlation	-.164	.064	.326**	1.000	-.042
	N	84	91	89	91	91
Baseline barriers subscale	Pearson Correlation	-.244*	-.659**	-.085	-.042	1.000
	N	86	92	89	91	93

Table 19. Correlations between adaptive coping and beliefs about utility of treatment, severity of illness, susceptibility to future complications, and barriers to adherence at baseline.

**Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

		Baseline approach coping	T2 utility subscale	T2 severity subscale	T2 susceptibility subscale	T2 barriers subscale
Baseline approach coping	Pearson Correlation	1.000	.173	.029	-.167	.098
	N	90	53	49	52	52
T2 utility subscale	Pearson Correlation	.173	1.000	.248	.011	.140
	N	53	60	55	58	59
T2 severity subscale	Pearson Correlation	.029	.248	1.000	.165	.164
	N	49	55	55	55	55
T2 susceptibility subscale	Pearson Correlation	-.167	.011	.165	1.000	-.216
	N	52	58	55	59	58
T2 barriers subscale	Pearson Correlation	.098	.140	.164	-.216	1.000
	N	52	59	55	58	60

Table 20. Correlations between adaptive coping and beliefs about utility of treatment, severity of illness, susceptibility to future complications, and barriers to adherence at post-treatment.

**Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

		Baseline approach coping	T3 utility	T3 severity	T3 susceptibility	T3 barriers
Baseline approach coping	Pearson Correlation	1.000	-.045	-.426**	-.361*	-.249
	N	90	41	41	41	41
T3 utility	Pearson Correlation	-.045	1.000	.148	.000	-.072
	N	41	44	44	44	44
T3 severity	Pearson Correlation	-.426**	.148	1.000	.364*	.303*
	N	41	44	45	45	45
T3 susceptibility	Pearson Correlation	-.361*	.000	.364*	1.000	.214
	N	41	44	45	45	45
T3 barriers	Pearson Correlation	-.249	-.072	.303*	.214	1.000
	N	41	44	45	45	45

Table 21. Correlations between adaptive coping and beliefs about utility of treatment, severity of illness, susceptibility to future complications, and barriers to adherence at post-treatment.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Linear regression analyses produced the following results: No predictive value of adaptive coping on beliefs about utility of treatment at either downstream time point. This was also true for beliefs about severity of illness. However, adaptive coping does predict beliefs about susceptibility of future complications at follow-up ($\beta = -.334$, $p < 0.01$). That is, the more adaptive coping, the less susceptible a patient believes he/she is to future oral complications. There was also a significant predictive relationship between adaptive coping and beliefs about barriers to treatment at post-treatment ($\beta = .291$, $p < 0.05$). That is the more adaptive coping at baseline, the more barriers were perceived at post-treatment (this might reflect a realistic view of what one will have to do to be able to

successfully adhere to oral care recommendations). This relationship was not significant at follow-up. No other significant results were found.

Maladaptive Coping

It was hypothesized that there would be a negative relationship between patients' maladaptive coping and the variables in the model. That is, the more maladaptive coping the poorer the intent to adhere, the worse the adherence to oral care recommendations, the more tobacco and alcohol use, and the less optimistic the illness perceptions.

a. It was predicted that there would be a negative relationship between maladaptive coping and intent to adhere at baseline, post-treatment, or follow-up. No significant correlations emerged between the two variables at any time point. See table 22. Similarly, linear regression analyses found no predictive relationships between maladaptive coping and intentions to adhere at either downstream time point.

		Baseline avoidant coping	Baseline intentions	T2 intentions	T3 intentions
Baseline avoidant coping	Pearson Correlation	1.000	-.062	-.034	.197
	N	90	84	52	42
Baseline intentions	Pearson Correlation	-.062	1.000	.175	-.031
	N	84	91	54	43
T2 intentions	Pearson Correlation	-.034	.175	1.000	.035
	N	52	54	60	37
T3 intentions	Pearson Correlation	.197	-.031	.035	1.000
	N	42	43	37	45

Table 22. Correlations between maladaptive coping and intentions to adhere at baseline, post-treatment, and follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

b. It was hypothesized that maladaptive coping and adherence to the recommended oral care regimen, at post-treatment and follow-up, would correlate negatively. There were no correlations between maladaptive coping and adherence to the oral care regimen at any time point. See table 23. Neither did linear regression analyses produce any significant predictive relationship between maladaptive coping and oral care at either post-treatment or follow-up.

		Baseline avoidant coping	Oral care at baseline	T2 ORAL CARE	T3 ORAL CARE
Baseline avoidant coping	Pearson Correlation	1.000	.094	-.139	-.181
	N	90	90	34	15
oral care at baseline	Pearson Correlation	.094	1.000	.336	.160
	N	90	97	38	17
T2 ORAL CARE	Pearson Correlation	-.139	.336	1.000	.612
	N	34	38	40	14
T3 ORAL CARE	Pearson Correlation	-.181	.160	.612	1.000
	N	15	17	14	17

Table 23. Correlations between maladaptive coping and oral care at baseline, post-treatment, and follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

c. Hypotheses predicted a positive relationship between tobacco use and maladaptive coping for those patients who smoked at baseline. There were no correlations between maladaptive coping and tobacco use at any time point. See table 24. Linear regression analyses revealed no significant predictive relationships between maladaptive coping and tobacco use at any of the downstream time points (note that N was too small for analyses for cigarette use at post-treatment and smokeless tobacco use at both post-treatment and follow-up.

		Baseline Cigarettes a day	T2 No of Cigarettes a day
Baseline avoidant coping	Pearson Correlation	.102	.031
	N	67	29

Table 24. Correlations between maladaptive coping and tobacco use at baseline, post-treatment, and follow-up. Correlations for smokeless tobacco use at each time point, and cigarette use at follow-up could not be computed because at least one of the variables was a constant.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

d. Likewise, a negative relationship was expected to emerge between maladaptive coping and alcohol use at post-treatment and follow-up. There were no correlations between maladaptive coping and alcohol use at any time point. See table 25. No significant predictive analyses emerged by linear regression analyses between maladaptive coping and alcohol use at any of the downstream time points.

		Baseline avoidant coping	Baseline monthly use of alcohol	T2 monthly use of alcohol	T3 monthly use of alcohol
Baseline avoidant coping	Pearson Correlation	1.000	.214	-.307	-.356
	N	90	38	10	17
Baseline monthly use of alcohol	Pearson Correlation	.214	1.000	.550	.708
	N	38	42	7	11
T2 monthly use of alcohol	Pearson Correlation	-.307	.550	1.000	a.
	N	10	7	10	1
T3 monthly use of alcohol	Pearson Correlation	-.356	.708	.	1.000
	N	17	11	1	18

Table 25. Correlations between maladaptive coping and alcohol use at baseline, post-treatment, and follow-up.
a. Cannot be computed because at least one of the variables is a constant.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

e. It was also hypothesized that maladaptive coping would be negatively related to patients' illness perceptions (baseline, post-treatment, and follow-up). There were no correlations between maladaptive coping and illness perceptions at any time point. See tables 26-29. Nor, did linear regression analyses produce any significant predictive relationships between maladaptive coping and beliefs about utility of treatment, severity of illness, susceptibility to future complications, and barriers to adherence at post-treatment and follow-up.

		Baseline avoidant coping	**Baseline external causes**	**Baseline internal causes**
Baseline avoidant coping	Pearson Correlation	1.000	-.011	.042
	N	90	86	87
Baseline external causes	Pearson Correlation	-.011	1.000	.459**
	N	86	92	92
Baseline internal causes	Pearson Correlation	.042	.459**	1.000
	N	87	92	94

Table 26. Correlations between maladaptive coping and causes of illness at baseline.
** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

		Baseline avoidant coping	Baseline utility subscale	Baseline severity subscale	Baseline susceptibility subscale	Baseline barriers subscale
Baseline avoidant coping	Pearson Correlation	1.000	-.142	-.004	.021	.165
	N	90	85	82	84	86
Baseline utility subscale	Pearson Correlation	-.142	1.000	.103	.064	-.659**
	N	85	92	89	91	92
Baseline severity subscale severe	Pearson Correlation	-.004	.103	1.000	.326**	-.085
	N	82	89	89	89	89
Baseline ADQ susceptibility subscale	Pearson Correlation	.021	.064	.326**	1.000	-.042
	N	84	91	89	91	91
Baseline barriers subscale	Pearson Correlation	.165	-.659**	-.085	-.042	1.000
	N	86	92	89	91	93

Table 27. Correlations between maldadaptive coping and beliefs about utility of treatment, severity of illness, susceptibility to future complications, and barriers to adherence at baseline.

**Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

		Baseline avoidant coping	T2 utility subscale	T2 severity subscale	T2 susceptibility subscale	T2 barriers subscale
Baseline avoidant coping	Pearson Correlation	1.000	.038	.058	-.136	.155
	N	90	52	49	51	52
T2 utility subscale	Pearson Correlation	.038	1.000	.248	.011	.140
	N	52	60	55	58	59
T2 severity subscale	Pearson Correlation	.058	.248	1.000	.165	.164
	N	49	55	55	55	55
T2 susceptibility subscale	Pearson Correlation	-.136	.011	.165	1.000	-.216
	N	51	58	55	59	58
T2 barriers subscale	Pearson Correlation	.155	.140	.164	-.216	1.000
	N	52	59	55	58	60

Table 28. Correlations between maladaptive coping and beliefs about utility of treatment, severity of illness, susceptibility to future complications, and barriers to adherence at post-treatment.

**Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

		Baseline avoidant coping	T3 utility	T3 severity	T3 susceptibility	T3 barriers
Baseline avoidant coping	Pearson Correlation	1.000	.272	-.182	-.202	.124
	N	90	42	42	42	42
T3 utility	Pearson Correlation	.272	1.000	.148	.000	-.072
	N	42	44	44	44	44
T3 severity	Pearson Correlation	-.182	.148	1.000	.364*	.303*
	N	42	44	45	45	45
T3 susceptibility	Pearson Correlation	-.202	.000	.364*	1.000	.214
	N	42	44	45	45	45
T3 barriers	Pearson Correlation	.124	-.072	.303*	.214	1.000
	N	42	44	45	45	45

Table29. Correlations between maladaptive coping and beliefs about utility of treatment, severity of illness, susceptibility to future complications, and barriers to adherence at follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Hypotheses Related to Illness Perceptions

Illness perceptions encompass 4 different subscales: beliefs about utility of treatment, severity of illness, susceptibility to future complications or illness, and barriers to adherence.

a. It was hypothesized that utility of treatment, severity of illness, and susceptibility to future complications would all be positively related to intent to adhere, but that barriers to illness would be negatively related to intent to adhere. There were a number of correlations between intent to adhere and illness perceptions. As predicted a positive correlation was found between beliefs about the utility of treatment ($r = .829$, $p < 0.01$) and intent to adhere at baseline. That is, the higher

the belief in the utility of the oral care regiment, the better the intents to adhere. This same relationship was also present at post-treatment ($r = .663$, $p < 0.01$). There was also a negative correlation between beliefs about barriers to adherence and intent to adhere at baseline ($r = -.788$, $p < 0.01$). There more barriers that are perceived, the less likely the intent to adhere. Post-treatment barriers were negatively correlated with intentions at baseline ($r = -.428$, $p < 0.01$). That is, the less intent to adhere at baseline, the more barriers were perceived at post-treatment with respect to future adherence. There were also significant negative correlations between baseline intent to adhere and follow-up beliefs about severity of illness ($r = -.341$, $p < 0.05$) and barriers to adherence ($r = -.382$, $p < 0.05$). In other words, the less intent to adhere at baseline the more severe the illness was perceived to be and the more barriers to adherence were perceived at follow-up. See tables 30-32.

		Baseline intentions	T2 intentions	T3 intentions
Baseline utility	Pearson Correlation	.829**	.106	-.001
	N	91	54	43
Baseline severity	Pearson Correlation	.151	-.148	.072
	N	89	53	42
Baseline susceptability	Pearson Correlation	.040	-.191	.000
	N	91	54	43
Baseline barriers	Pearson Correlation	-.788**	-.206	-.030
	N	91	54	43

Table 30. Correlations between baseline beliefs about utility of treatment, severity of illness, susceptibility to future complications, barriers to adherence and intent to adhere at baseline, post-treatment, and follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

		Baseline intentions	T2 intentions	T3 intentions
T2 utility	Pearson Correlation	.170	.663**	-.031
	N	54	59	37
T2 severity	Pearson Correlation	-.072	.085	.215
	N	49	55	34
T2 susceptibility	Pearson Correlation	.058	.072	-.119
	N	53	59	36
T2 barriers	Pearson Correlation	-.428**	.107	.282
	N	54	59	38

Table 31. Correlations between post-treatment beliefs about utility of treatment, severity of illness, susceptibility to future complications, barriers to adherence and intent to adhere at baseline, post-treatment, and follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

		Baseline intentions	T2 intentions	T3 intentions
T3 utility	Pearson Correlation	-.270	-.306	.269
	N	42	36	44
T3 severity	Pearson Correlation	-.341*	.006	-.224
	N	43	37	45
T3 susceptibility	Pearson Correlation	-.242	-.063	-.118
	N	43	37	45
T3 barriers	Pearson Correlation	-.382*	-.166	.077
	N	43	37	45

Table 32. Correlations between follow-up beliefs about utility of treatment, severity of illness, susceptibility to future complications, barriers to adherence and intent to adhere at baseline, post-treatment, and follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Regression analyses were conducted to test the predictive value of beliefs about utility of treatment, severity of illness, susceptibility to future complications,

and barriers to adherence on intent to adhere. Illness perceptions did not emerge as significant predictors of intent to adhere at either post-treatment or follow-up.

b. It was hypothesized that utility of treatment, severity of illness, and susceptibility to future complications would all be positively related to oral care, whereas barriers to adhere would be negatively related to oral care. A significant negative relationship emerged between baseline beliefs about the severity of illness and follow-up oral care. That is the more severe the illness is perceived to be, the less likely a patient was to practice good oral care at follow-up ($r = -.540$, $p < 0.05$). See table 33. Regression analyses with illness perceptions as the independent variable produced the following results: Beliefs about utility of treatment, susceptibility to future complications, and barriers to adherence did not emerge as a significant predictor of oral care at either post-treatment or follow-up. Severity of illness was a significant predictor of oral care at follow-up ($\beta = -.549$, $p < 0.05$). That is, the more severe the illness was perceived to be, the less likely a patient was to follow the oral care recommendations (does patient give up in the face of what is perceived to be a severe illness or do patients who correctly identify their illness as severe suffer more treatment side effects, as a consequence of more prolonged treatment, that in turn prevents adherence?).

		oral care at baseline	T2 Oral care	T3 oral care
Baseline utility	Pearson Correlation	.003	-.019	-.394
	N	92	36	15
Baseline severity	Pearson Correlation	-.022	-.326	-.540*
	N	89	35	14
Baseline barriers	Pearson Correlation	.091	.081	-.083
	N	93	36	15
Baseline susceptability	Pearson Correlation	-.084	-.042	-.192
	N	91	36	15
T2 utility	Pearson Correlation	-.086	.192	.240
	N	57	38	15
T2 severity	Pearson Correlation	-.013	.011	-.248
	N	52	35	15
T2	Pearson Correlation	-.064	-.015	-.295
	N	56	38	16
T2 barriers	Pearson Correlation	-.019	.189	.288
	N	57	38	16
T3 utilityl	Pearson Correlation	.227	-.250	-.058
	N	44	24	14
T3 severity	Pearson Correlation	-.115	-.080	-.072
	N	45	25	15
T3 susceptibility	Pearson Correlation	-.204	-.138	-.477
	N	45	25	15
T3 barriers	Pearson Correlation	-.207	.107	.090
	N	45	25	15

Table 33. Correlations between baseline, post-treatment, and follow-up beliefs about utility of treatment, severity of illness, susceptibility to future complications, barriers to adherence and oral care at baseline, post-treatment, and follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

c. It was hypothesized that utility of treatment, severity of illness, and susceptibility to future complications would all be negatively related to tobacco use, but that

barriers to illness would be positively related to cessation of tobacco use (post-treatment and follow-up). Baseline illness perceptions were significantly correlated with tobacco use at post-treatment as follows: The higher the belief in the utility of treatment, the more reported tobacco use (does pt believe that treatment can counter effects of smoking?) ($r = .381$, $p < 0.05$). The more severe the illness is believed to be, the more reported tobacco use (does pt believe that smoking doesn't matter since illness is so severe?) ($r = .431$, $p < 0.05$). The more barriers to adherence; the less reported tobacco use (the more difficult the oral care regimen is perceived to be, the better patients are at refraining from smoking?) ($r = -.411$, $p < 0.05$). There were no significant correlations for follow-up tobacco use. See table 34.

		Baseline Cigarettes	T2 Cigarettes
Baseline utility	Pearson Correlation	.151	.381*
	N	65	29
Baseline severity	Pearson Correlation	.035	.431*
	N	63	29
Baseline susceptability	Pearson Correlation	.022	.226
	N	65	29
Baseline barriers	Pearson Correlation	-.008	-.411*
	N	66	29
T2 utility	Pearson Correlation	.119	.018
	N	41	31
T2 severity	Pearson Correlation	.083	-.048
	N	36	27
T2 susceptibility	Pearson Correlation	-.058	-.014
	N	40	30
T2 support	Pearson Correlation	.016	-.179
	N	41	32
T3 utility	Pearson Correlation	.008	a.
	N	33	18
T3 severity	Pearson Correlation	.013	a.
	N	34	19
T3 susceptibility	Pearson Correlation	.039	a.
	N	34	19
T3 barriers	Pearson Correlation	.106	a.
	N	34	19

Table 34. Correlations between baseline, post-treatment, and follow-up beliefs about utility of treatment, severity of illness, susceptibility to future complications, barriers to adherence and cigarette use at baseline and post-treatment. Correlations for smokeless tobacco use at each time point, and cigarette use at follow-up could not be computed because at least one of the variables was a constant.

**Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Regression analyses were conducted to test the predictive value of illness perceptions and tobacco use. Beliefs about the utility of treatment did predict cigarette use at post-treatment ($\beta = .407$, $p < 0.05$). That is, the higher the belief that treatment is useful, the more reported cigarette use (does pt believe that treatment is so powerful that it will cancel out bad effects of smoking?). This relationship was not significant at follow-up, or for smokeless tobacco at any time

point (because the sample size was too small and the variable ended up representing a constant). Beliefs about the severity of illness also emerged as a significant predictor cigarette/cigar use at post-treatment ($\beta = .431$, $p < 0.05$). That is, the more severe the illness is perceived to be, the more the reported use of cigarettes (again, does patient give up in the face of what is perceived to be a very severe illness?). This relationship was not reproduced for cigarettes at follow-up or for smokeless tobacco use (again due to a small sample size the variable ended up representing a constant). Beliefs about susceptibility to future complications did not predict tobacco use at either post-treatment or follow-up. Beliefs about barriers to adherence did emerge as a significant predictor of post-treatment cigarette use ($\beta = -.505$, $p < 0.05$). The more barriers are perceived at baseline, the less the reported use of cigarettes at post-treatment. There were no other significant relationships between beliefs about barriers to adherence and tobacco use at post-treatment or follow-up.

d. It was hypothesized that utility of treatment, severity of illness, and susceptibility to future complications would all be negatively related to alcohol use, but that barriers to illness would be positively related to cessation of alcohol use (post-treatment and follow-up). There was a significant negative correlation between baseline beliefs about barriers to adherence and follow-up alcohol use($r = -.566$, $p < 0.05$). That is, the more barriers are perceived at baseline, the less reported alcohol use at follow-up. There was also a significant correlation between baseline alcohol use and beliefs about the utility of treatment at post-treatment ($r = -.520$, $p < 0.01$). That is the more reported alcohol use at baseline, the lower the

belief in the utility of treatment at post-treatment. See table 35. Regression analyses tested the predictive value of illness perceptions on alcohol use. Beliefs about utility of treatment, severity of illness, and susceptibility to future complications did not emerge as significant predictors of alcohol use at either post-treatment or follow-up. However, there was a significant predictive relationship between beliefs about barriers to adherence and alcohol use at follow-up ($\beta = -.520$, $p < 0.05$). That is, the more barriers were perceived at baseline, the less alcohol use was reported at follow-up. This relationship was not present at post-treatment.

		Baseline alcohol use	T2 alcohol use	T3 alcohol use
Baseline utility	Pearson Correlation	-.185	.147	-.036
	N	42	9	17
Baseline severity	Pearson Correlation	.294	.385	-.174
	N	39	8	17
Baseline susceptability	Pearson Correlation	.201	.067	-.022
	N	41	9	17
Baseline barriers	Pearson Correlation	.113	-.120	-.566*
	N	42	9	17
T2 utility	Pearson Correlation	-.520**	-.420	-.368
	N	29	10	15
T2 severity	Pearson Correlation	.141	-.154	.040
	N	25	9	12
T2 susceptibility	Pearson Correlation	.199	.391	-.030
	N	27	10	13
T2 barriers	Pearson Correlation	-.306	-.394	-.411
	N	28	10	15
T3 utility	Pearson Correlation	.347	.296	-.416
	N	22	5	17
T3 severity	Pearson Correlation	.170	.282	-.284
	N	22	5	17
T3 susceptibility	Pearson Correlation	.368	.418	-.135
	N	22	5	17
T3 barriers	Pearson Correlation	.150	-.524	-.239
	N	22	5	17

Table 35. Correlations between baseline, post-treatment, and follow-up beliefs about utility of treatment, severity of illness, susceptibility to future complications, barriers to adherence and alcohol use at baseline, post-treatment, and follow-up.
**Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

e. Finally, it was hypothesized that a positive relationship would emerge between beliefs about the utility of treatment, the severity of illness, and susceptibility to

future complications and overall self-reported adherence, whereas there would be a negative correlation between barriers to adherence and overall self-reported adherence. Correlation analyses revealed several significant relationships between illness perceptions and overall self-reported adherence. There was a significant positive correlation between belief in utility of treatment at baseline, and overall adherence reported at post-treatment ($r = .362$, $p < 0.01$). A negative correlation also emerged between barriers perceived at baseline, and overall adherence is reported at post treatment ($r = -.587$, $p < 0.01$). The more overall adherence at post-treatment was correlated with fewer barriers perceived at follow-up ($r = -.396$, $p < 0.05$), and finally, post-treatment beliefs about severity were positively correlated with follow-up overall adherence ($r = .369$, $p < 0.05$). See table 36. However, regression analyses failed to produce any significant findings with respect to the predictive value of illness perceptions on overall self-reported adherence at either post-treatment or follow-up.

		T2 overall adherence	T3 overall adherence
Baseline utility	Pearson Correlation	.362**	.016
	N	51	42
Baseline severity	Pearson Correlation	-.024	-.055
	N	50	41
Baseline susceptibility	Pearson Correlation	-.204	.206
	N	51	42
Baseline barriers	Pearson Correlation	-.587**	-.294
	N	51	42
T2 utility	Pearson Correlation	.209	.064
	N	54	36
T2 severity	Pearson Correlation	-.039	.368*
	N	50	35
T2 susceptibility	Pearson Correlation	-.002	.319
	N	54	37
T2 barriers	Pearson Correlation	-.070	.156
	N	54	37
T3 utility	Pearson Correlation	.178	-.200
	N	34	41
T3 severity	Pearson Correlation	-.212	.046
	N	35	42
T3 susceptibility	Pearson Correlation	-.310	.125
	N	35	42
T3 barriers	Pearson Correlation	-.396*	-.244
	N	35	42

Table 36. Correlations between baseline, post-treatment, and follow-up beliefs about utility of treatment, severity of illness, susceptibility to future complications, barriers to adherence and overall adherence at post-treatment and follow-up.

**Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

Hypotheses Related to Intent to Adhere

With regard to the intent to adhere is was hypothesized that baseline intent to adhere with doctors' recommendations would be positively related to actual adherence to each of the outcome variables (oral care, tobacco, use, and alcohol use) as well as self-reported overall adherence.

a. It was predicted that there would be a positive relationship between intent to adhere and oral care at each time point. There was a significant correlation between oral care at post-treatment and intentions to adhere at follow-up ($r = .460$, $p < 0.05$). That is, the better the oral care was at post-treatment, the better the intentions to continue good oral care at follow-up. Oral care at follow-up was also significantly correlated with intentions to adhere at follow-up ($r = .718$, $p < 0.01$). See table 37. However, regression analyses did not reveal any significant findings with respect to the predictive value of intentions to adhere on oral care at either post-treatment or follow-up, nor did intentions at post-treatment predict oral care at follow-up.

		Baseline intentions	T2 intentions	T3 intentions
Oral care at baseline	Pearson Correlation	-.131	-.175	.081
	Sig. (2-tailed)	.217	.193	.599
	N	91	57	45
T2 oral care	Pearson Correlation	-.124	.042	.460*
	Sig. (2-tailed)	.471	.799	.021
	N	36	39	25
T3 oral care	Pearson Correlation	.326	.120	.718**
	Sig. (2-tailed)	.236	.659	.003
	N	15	16	15

Table 37. Correlations between intent to adhere at baseline, post-treatment, and follow-up and oral care at baseline, post-treatment, and follow-up.
* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

b. It was expected that there would be a negative relationship between intentions to adhere and tobacco use, so that the better the intentions, the less a patient would smoke. What was found was the opposite; a positive correlation between baseline intent to adhere and post-treatment tobacco use ($r = .431$, $p < 0.05$). That is, the better the intentions to adhere at baseline, the more reported cigarette use at post-treatment. See table 38. Linear regression analyses revealed that intentions to adhere at baseline significantly predict cigarette use at post-treatment ($\beta = .464$, $p < 0.01$). There were no other significant relationships between intentions to adhere at baseline, or post-treatment, and tobacco use.

		Baseline Cigarettes	T2 Cigarettes
Baseline intentions	Pearson Correlation	.116	.413*
	N	65	29
T2 intentions	Pearson Correlation	.023	-.018
	N	41	31
T3 intentions	Pearson Correlation	.071	a.
	N	34	19

Table 38. Correlations between intent to adhere at baseline, post-treatment, and follow-up and tobacco use at baseline, post-treatment, and follow-up. Correlations for smokeless tobacco use at each time point, and cigarette use at follow-up could not be computed because at least one of the variables was a constant.
a. Cannot be computed because at least one of the variables is a constant.
* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

c. A negative correlation emerged between post-treatment intent to adhere and follow-up alcohol use ($r = -.585$, $p < 0.05$). That is, the better the intent to adhere at post-treatment, the less alcohol use was reported at follow-up. There was also a negative correlation between baseline alcohol use and post-treatment intentions to adhere ($r = -.510$, $p < 0.01$). That is, the more alcohol use reported by the patient

at baseline, the less the intent to adhere at post-treatment. See table 39. Regression analyses found no significant predictive relationships between intentions to adhere and alcohol use at any time point.

		Baseline alcohol	T2 alcohol	T3 alcohol
Baseline intentions	Pearson Correlation	-.145	-.348	a.
	N	41	9	17
T2 intentions	Pearson Correlation	-.510**	.032	-.585*
	N	28	10	14
T3 intentions	Pearson Correlation	-.259	-.818	-.425
	N	22	5	17

Table 39. Correlations between intent to adhere at baseline, post-treatment, and follow-up and alcohol use at baseline, post-treatment, and follow-up.
a. Could not be computed because at least one of the variables was a constant.
* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

d. A positive relationship was hypothesized between intent to adhere and overall self-reported adherence. There was a positive correlation between intent to adhere at baseline ($r = .602$, $p < 0.01$), post-treatment ($r = .332$, 0.05), and follow-up ($r = .348$, $p < 0.05$) and post-treatment overall self-reported adherence. There was also a significant correlation between post-treatment intentions to adhere and overall self-reported adherence at follow-up ($r = .602$, 0.05). See table 40.

		Baseline intentions	T2 intentions	T3 intentions
T2 overall adherence	Pearson Correlation	.602**	.332*	.348*
	N	51	55	35
T3 overall adherence	Pearson Correlation	.278	.378*	-.020
	N	42	37	42

Table 40. Correlations between intent to adhere at baseline, post-treatment, and follow-up and overall self-reported adherence at baseline, post-treatment, and follow-up.
* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Linear regressing analyses produced the following results. There was a significant predictive relationship between post-treatment intentions to adhere and follow-up self-reported adherence ($\beta = .366$, $p < 0.05$). The better the intentions to adhere at post-treatment, the better the self-reported adherence at follow-up (this might be a reflection of improved oral functional status, though technically you would expect oral complications from XRT to be the worst right at the end of treatment).

Summary of proposed Model

The illustration below presents a summary of findings as they pertain to the predictive model that was examined in this study.

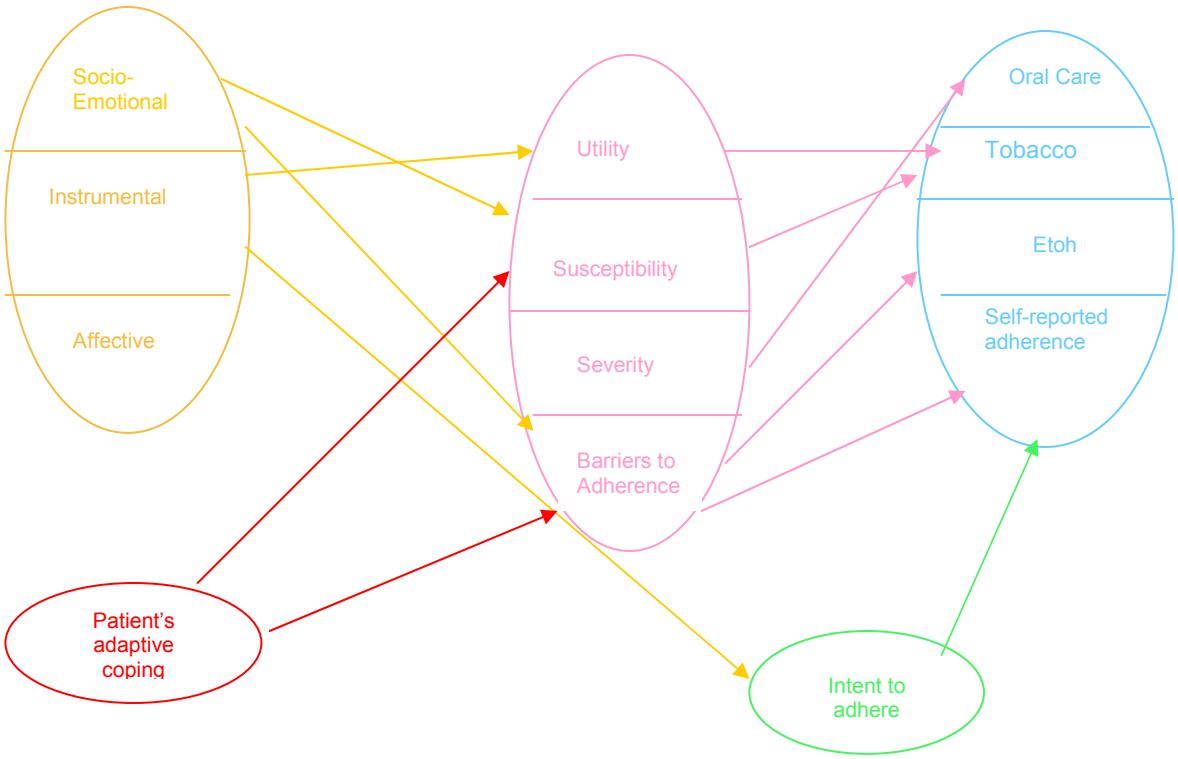

Figure 2.

While the model itself did not explain factors that may lead to adherence, it is important to note that several of the paths in the model were found to be significant. Such findings ought to help guide future research in the area of oral care among head and neck cancer patients. The rest of this chapter will discuss findings of exploratory analyses.

Exploratory Questions

Exploratory analyses examined the relationships of depression, cancer site, treatment modality, and functional status on other variables in the model. Zero-order correlations and predictive statistics are reported for depressions and oral functional status below. GLM repeated measures and univariate analyses examined the effect of cancer site and treatment modality on major variables of the model.

Depression

Correlation analyses between depression and variables in the model produced the following correlations. Baseline depression was positively correlated with both post-treatment ($r = .320$, $p < 0.05$) and follow-up depression ($r = .325$, $p < 0.05$). A correlation was found between socio-emotional behavior of the doctor and reported depression at baseline ($r = -.269$, $p < 0.05$), but not at post-treatment or follow-up. That is, the better the doctor's behavior was perceived to be, the less depression was reported. A significant correlation emerged between baseline depression and baseline avoidant coping ($r = .569$, $p < 0.01$), baseline maladaptive coping and follow-up depression ($r = .314$, $p < 0.05$), and between baseline depression and baseline adaptive coping ($r = -.343$, $p < 0.01$). Baseline depression is also correlated ($r = -.314$, $p < 0.05$) with post-treatment beliefs about the utility of treatment. No other significant correlations were found between illness

perceptions and depression at any time point. There is a significant correlation between baseline oral care and follow-up depression ($r = .343$, $p < 0.05$), but no other correlations between depression and oral care at any time point. There are no significant relationships between depression and tobacco use at any time point. Depression and alcohol use is positively correlation at baseline ($r = .343$, $p < 0.05$), but negatively correlated at follow-up ($r = -.597$, $p < 0.05$). There is a significant correlation between depression at post-treatment and overall self-reported adherence at follow-up ($r = -.407$, $p < 0.05$). There were no significant correlations between intentions to adhere and depression at any time point. Finally, baseline depression is correlated with baseline oral functional status ($r = .262$, $p < 0.05$). This same relationship is also significant at post-treatment ($r = .469$, $p < 0.01$) and at follow-up ($r = .594$, $p < 0.01$). See tables 41- 45.

		Baseline CESD	T2 CESD	T3 CESD
Baseline utility	Pearson Correlation	-.173	.125	.113
	N	84	50	43
Baseline severity	Pearson Correlation	.060	.010	.040
	N	82	49	42
Baseline susceptibility	Pearson Correlation	.182	.153	-.105
	N	83	50	43
Baseline barriers	Pearson Correlation	.185	-.220	.090
	N	85	50	43
T2 utility	Pearson Correlation	-.314*	.006	-.044
	N	51	51	37
T2 severity	Pearson Correlation	-.001	-.205	.115
	N	47	47	35
T2 susceptibility	Pearson Correlation	-.166	.005	-.177
	N	50	50	37
T2 barriers	Pearson Correlation	.066	-.210	-.004
	N	50	52	38
T3 utility	Pearson Correlation	.210	.221	-.188
	N	40	35	42
T3 severity	Pearson Correlation	.179	-.083	-.157
	N	40	36	43
T3 susceptibility	Pearson Correlation	.071	-.039	.079
	N	40	36	43
T3 barriers	Pearson Correlation	.031	-.002	.214
	N	40	36	43

Table 41. Correlations between depression at baseline, post-treatment, and follow-up and illness perceptions baseline, post-treatment, and follow-up.
* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

		Baseline avoidant coping	Baseline approach coping	External causes of illness	Internal causes of illness
Baseline CESD	Pearson Correlation	.569**	-.343**	.137	.037
	N	86	86	83	85
T2 CESD	Pearson Correlation	.269	-.026	.183	.048
	N	47	47	49	50
T3 CESD	Pearson Correlation	.314*	-.127	.179	.079
	N	43	41	43	43

Table 42. Correlation matrix for depression at baseline, post-treatment, and follow-up with coping and beliefs about causes of illness.
* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

		Baseline oral care	T2 oral care	T3 oral care	Baseline alcohol use	T2 alcohol use	T3 alcohol use
Baseline CESD	Pearson Correlation	.089	-.164	-.169	.343*	-.119	-.115
	N	88	34	13	38	9	16
T2 CESD	Pearson Correlation	.215	-.310	-.127	.360	-.072	.103
	N	52	34	14	25	9	16
T3 CESD	Pearson Correlation	.343*	-.024	-.199	.350	-.075	-.597*
	N	45	25	15	22	6	17

Table 43. Correlation matrix for depression at baseline, post-treatment, and follow-up with oral care and alcohol use at each time point.

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

		T2 self-reported adherence	T3 self-reportd adherence	Baseline FactHN	T2 FACTHN	T3 FACTHN
Baseline CESD	Pearson Correlation	.105	-.026	.262*	.135	.074
	N	49	40	87	51	40
T2 CESD	Pearson Correlation	-.059	-.407*	.162	.469**	.103
	N	48	35	50	51	35
T3 CESD	Pearson Correlation	-.029	-.277	-.176	.357*	.594**
	N	36	43	43	37	43

Table 44. Correlation matrix for depression at baseline, post-treatment, and follow-up with self-reported adherence and oral complications (FACTHN).

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

		Baseline intentions	T2 intentions	T3 intentions
Baseline CESD	Pearson Correlation	-.143	-.269	.051
	N	83	51	40
T2 CESD	Pearson Correlation	.081	-.156	-.236
	N	50	51	36
T3 CESD	Pearson Correlation	.043	-.218	.054
	N	43	38	43

Table 45. Correlation matrix for depression at baseline, post-treatment, and follow-up with intentions to adhere at each timepoint.

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

In regression analyses, depression at baseline did not predict beliefs about utility of treatment, severity of illness, or barriers to adherence at either post-treatment or at follow-up. Neither did post-treatment depression predict follow-up beliefs about utility of treatment, severity of illness, susceptibility to future complications, or barriers to adherence. Baseline depression did emerge as a significant predictor of post-treatment beliefs about susceptibility ($\beta = -.259$, $p < 0.05$). That is, the less depression at baseline, the more susceptible patient believes he/she is to future complications at post-treatment. This relationship did not replicate at follow-up. No significant regressions were found for baseline depression and intent to adhere at either post-treatment or follow-up. However, post-treatment depression did predict follow-up intentions to adhere ($\beta = -.373$, $p < 0.05$). That is, the more depressed at post-treatment, the lower the intent to adhere at follow-up. Regression analyses between depression and oral care, tobacco use, and alcohol use did not produce any significant relationships.

Oral Functional Status

Functional status relates to variables in the model as follows: There was a significant correlation between oral functional status and the affective quality of doctor-patient communication at baseline ($r = -.242$, $p < 0.05$). No relationships were found between coping and oral functional status or between patients' beliefs about the causes of illness and oral functional status. With respect to illness perceptions the following relationships emerged. Baseline oral functional status was correlated with baseline beliefs about susceptibility to future oral complications ($r = -.248$, $p < 0.05$), post-treatment beliefs

about susceptibility to future oral complications ($r = -.373$, $p < 0.01$), and follow-up beliefs about susceptibility ($r = -352$, $p < 0.05$). Post-treatment oral functional status was correlated with baseline beliefs about barriers to adherence ($r = .293$, $p < 0.05$), and follow-up oral functional status was correlated with follow-up beliefs about susceptibility ($r = -.480$, $p < 0.05$). There were no other significant relationships between functional status and illness perceptions at any other time point. Functional status was also related to intentions to adhere. Specifically, baseline functional status was positively correlated with baseline intentions to adhere ($r = .255$, $p < 0.05$). Post-treatment intents to adhere were correlated with follow-up intentions to adhere ($r = -.350$, $p < 0.05$). Follow-up functional status was not related to intentions to adhere. Only one correlation was found between functional status and oral care. Baseline oral care was significantly correlated with baseline functional status ($r = .256$, $p < 0.05$). There were no significant correlations between functional status and tobacco use or alcohol use at any time points, nor were there any significant relationships between oral functional status and self-reported adherence or oral functional status and depression. See tables 46-54.

		Instrumental information	Socio-emotional behavior	Affective quality
Baseline FACTHN	Pearson Correlation	.079	.117	-.242*
	N	78	79	75
T2 FACTHN	Pearson Correlation	.145	.173	-.238
	N	46	47	45
T3 FACTHN	Pearson Correlation	.256	.224	-.094
	N	38	38	34

Table 46. Correlation matrix between oral functioning and doctor-patient communication.
* Correlation is significant at the 0.05 level (2-tailed)
** Correlation is significant at the 0.01 level (2-tailed).

		External Causes	Internal Causes	Baseline avoidant coping	Baseline approach coping
Baseline FACHN	Pearson Correlation	-.021	.009	.101	.108
	N	82	83	82	81
T2 FACTHN	Pearson Correlation	-.089	-.096	.262	.070
	N	47	48	47	47
T3 FACTHN	Pearson Correlation	.023	-.075	.144	.052
	N	38	38	35	35

Table 47. Correlation matrix between oral functional status, beliefs about causes of illness, and coping.

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

		Baseline ADQ utility subscale	Baseline ADQ severity subscale severe	Baseline ADQ susceptibility subscale	Baseline ADQ barriers subscale
Baseline FACTHN	Pearson Correlation	.071	-.163	-.248*	.081
	N	82	79	81	83
T2 FACTHN	Pearson Correlation	-.191	-.272	-.120	.293*
	N	47	46	47	47
T3 FACTHN	Pearson Correlation	.105	-.220	-.290	.079
	N	39	38	38	39

Table 48. Correlation matrix between oral functional status and illness perceptions at baseline.

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

		T2 ADQ utility subscale	T2 ADQ severity subscale	T2 ADQ susceptibility subscale	T2 ADQ barriers subscale
Baseline FACTHN	Pearson Correlation	.113	.101	-.373**	.214
	N	51	47	49	51
T2 FACTHN	Pearson Correlation	-.024	-.033	-.275	.115
	N	50	47	49	50
T3 FACTHN	Pearson Correlation	.273	.118	-.196	.183
	N	24	21	23	25

Table 49. Correlation matrix between oral functional status and illness perceptions at post-treatment.

** Correlation is significant at the 0.01 level (2-tailed).

		T3 ADQ Utility subscale	T3 ADQ Severity subscale	T3 ADQ Susceptibility subscale	T3 ADQ barriers subscale
Baseline FACTHN	Pearson Correlation	-.066	-.163	-.352*	-.030
	N	43	43	43	43
T2 FACTHN	Pearson Correlation	.169	.005	-.325	.117
	N	36	36	36	36
T3 FACTHN	Pearson Correlation	.028	-.097	-.480*	.142
	N	20	21	21	21

Table 50. Correlation matrix between oral functional status and illness perceptions at follow-up.
* Correlation is significant at the 0.05 level (2-tailed).

		Baseline intentions	T2 intentions	*T3 intentions*
Baseline FACTHN	Pearson Correlation	.255*	.021	-.053
	N	81	50	43
T2 FACTHN	Pearson Correlation	.083	-.220	-.350*
	N	47	50	36
T3 FACTHN	Pearson Correlation	.019	-.278	.219
	N	38	24	21

Table 51. Correlation matrix between oral functional status and intentions to adhere at each time point.
* Correlation is significant at the 0.05 level (2-tailed).

		Oral care at baseline	T2 Oral care	T3 Oral care
BLFHN	Pearson Correlation	.256*	.213	.231
	N	86	33	15
T2FHN	Pearson Correlation	.018	-.140	.126
	N	50	32	15
T3FHN	Pearson Correlation	-.064	.281	.404
	N	39	15	10

Table 52. Correlation matrix between oral functional status and oral care at each time point.
* Correlation is significant at the 0.05 level (2-tailed).

		Baseline FACTHN	T2 FACTHN	T3 FACTHN
Baseline cigarettes per day	Pearson Correlation	-.194	-.155	-.037
	N	64	35	29
Baseline monthly Alcohol use	Pearson Correlation	.060	.154	-.505
	N	37	25	13
T2 cigarettes per day	Pearson Correlation	.097	a.	.048
	N	26	24	14
T2 monthly alcohol use	Pearson Correlation	-.439	-.246	-.945
	N	10	10	3
T3 monthly alcohol use	Pearson Correlation	-.049	.126	.029
	N	17	15	9

Table 53. Correlation matrix between oral functional status, tobacco use, and alcohol use at each time point. Correlations for smokeless tobacco at each time point and follow-up cigarette use could not be calculated. Due to a small N, the variable ended up representing a constant.

a Cannot be computed because at least one of the variables is constant.

		Baseline CESD	T2 CESD	T3 CESD
Baseline FACTHN	Pearson Correlation	.049	-.075	.232
	N	80	48	43
T2 FACTHN	Pearson Correlation	.224	.143	.115
	N	45	47	37
T3 FACTHN	Pearson Correlation	.106	-.023	.267
	N	35	25	20

Table 54. Correlation matrix between oral functional status and depression at each time point.

		T2 Self-reported adherence	T3 Self-reported adherence
Baseline FACTHN	Pearson Correlation	.177	.041
	N	47	42
T2 FACTHN	Pearson Correlation	-.124	-.047
	N	46	36
T3 FACTHN	Pearson Correlation	-.004	-.079
	N	22	20

Table 54. Correlation matrix between oral functional status and self reported adherence at post-treatment and follow-up.

Oral functioning did not predict depression, coping, oral care, tobacco use, alcohol use, or overall self-reported adherence at post-treatment or follow-up. There was a significant predictive relationship between oral functioning and the affective quality of doctor-patient communication at post-treatment, with the affective quality of doctor-patient communication predicting post-treatment oral functioning (β = -.570, $p < 0.05$). That is, the less satisfied patients were with the affective quality of the communication, the more discomfort they reported at post-treatment. Oral functioning at baseline emerged as a significant predictor of beliefs about susceptibility to future oral complications (β = -.386, $p < 0.05$). That is, the more oral complications at baseline, the weaker the belief in the utility of the oral care regimen at post-treatment. This relationship was also significant at follow-up (β = -.350, $p < 0.05$). At post-treatment oral functioning predicted follow-up beliefs about utility of treatment (β = .401, $p < 0.01$), susceptibility to future complications (β = -.549, $p < 0.01$), and barriers to adherence (β = .352, $p < 0.05$). Post-treatment oral functional status also predicted follow-up intentions to adhere (β = -.561, $p < 0.01$). That is, the more complications at post-treatment, the less the intent to adhere at follow-up.

Cancer Site

GLM univariate analyses were run to test the predictive value of cancer site on doctor-patient communication, coping, and beliefs about the causes of illness at baseline. No significant results were found with respect to any of the three variables. GLM univariate analyses were also run for oral care at each time point, as N was too small for repeated

measures analyses. No group differences emerged with respect to oral care. Finally, univariate analyses were run at baseline for tobacco use and alcohol use, as N was too small for analyses at both post-treatment and follow-up. There were no effects of cancer site on any of the two outcome variables.

GLM repeated measures analyses were conducted to examine the predictive value of cancer site on depression, oral functional status, illness perceptions, and intent to adhere. There were no group differences for depression at any time point. With respect to oral functional status there was a main effect of cancer site ($F(1,59) = 12.06$, $p < 0.01$), so that patients with oral cancer (mean = 28.83) reported significantly less problems than those with oralpharyngeal cancer (mean = 32.05) at baseline, but not at post-treatment or follow-up. The FACT-HN assesses symptoms for both the oral cavity and the throat, thus it is difficult to explain this finding. Repeated measures analyses did not reveal any group differences by cancer site on illness perceptions or intent to adhere.

Treatment Modality

GLM univariate analyses were run to test the predictive value of treatment modality on doctor-patient communication, coping, and illness perceptions at baseline. No significant results were found for treatment modality with respect to doctor-patient communication, coping, or illness perceptions. GLM univariate analyses were also run for oral care at each time point, as N was too small for repeated measures analyses. No group differences emerged. Finally, univariate analyses were run at baseline for tobacco use and alcohol use, as N was too small for repeated measures analyses at both post-

treatment and follow-up. There were no effects of treatment modality on any of the two outcome variables.

GLM repeated measures analyses were conducted for treatment modality with respect to depression, oral functional status, and illness perceptions. There were no significant group differences for depression, oral functional status, illness perceptions, or intentions to adhere at any time point.

Mediation Analyses

It was hypothesized that patients' illness perceptions would operate as a partial mediator of the relationship between patients' perceptions of each aspect of the doctor-patient communication (socio-emotional quality, affective quality, and instrumental information) and patient adherence. Linear regression analyses were conducted between the independent variable, adherence, and dependent variable, doctor-patient communication, and between the independent variable and the proposed mediator to determine whether the relationships would be appropriate (i.e. were significant) for mediational analysis.

It was hypothesized that patients' illness perceptions would emerge as a partial mediator of the relationship between patients' perceptions of the socio-emotional quality, the affective quality, and the instrumental quality of the doctor-patient communication, at baseline, and each of the outcome variables. There were no significant regressions between any of the three aspects of doctor-patient communication and oral care, tobacco use, or alcohol use at either post-treatment or follow-up, thus, according to Baron and Kenney (1986), mediational analysis was not deemed appropriate.

Moderation Analyses

Patients' adaptive coping was hypothesized to strengthen the relationship between each aspect of the doctor-patient communication (socio-emotional quality, affective quality, and instrumental information) and patient adherence. Linear regression analyses were conducted to ensure that moderational analysis would be appropriate. That is, there is a significant predictive relationship between the independent variable and the dependent variables. According to Baron and Kenny (1986) it is also preferable that the moderator be uncorrelated with the independent variable and the dependent variable or, at the very least, that these relationships are weak.

It was hypothesized that patients' coping would moderate the relationship between patients' perceptions of each aspect of the doctor-patient communication, at baseline, and the adherence measures at post-treatment and follow-up. The moderator, adaptive coping, was not significantly correlated with the independent variable, doctor-patient communication, or the any of the dependent variables, oral care, tobacco use, and alcohol use. However, no significant predictive relationships were found for any of the three aspects of doctor-patient communication and any of the dependent variables at post-treatment and follow-up. Nevertheless, moderation analyses were conducted. No significant findings emerged.

Finally, exploratory questions had also aimed to investigate the effect of depression and functional status on the relationships between variables in the proposed model. It was proposed that depression and oral functional status would each emerge as moderators between:

a. Patients' perceptions of doctor-patient communication and patient adherence. Linear regressions did not reveal any significant predictive relationship between any of the aspects of doctor-patient communication and actual patient adherence at post-treatment or follow-up. Nonetheless, moderation analyses were performed. There were no significant findings for either depression or oral functional status.

b. Patients' illness perceptions and patient adherence. Linear regressions revealed significant predictive relationships between baseline beliefs about severity of illness and oral care at post-treatment, baseline beliefs about severity of illness and cigarette use at post-treatment, baseline beliefs about the utility of treatment and cigarette use at post-treatment, baseline beliefs about barriers to adherence and cigarette use at post-treatment, and baseline beliefs about barriers to adherence and alcohol use at follow-up. Regression analyses found that oral functional status moderates the relationship between beliefs about the severity of illness and actual oral care at post-treatment ($\beta = -2.132$, $p < 0.05$). That is, when oral functional status is good, beliefs about severity of illness is a good predictor of adherence, whereas when oral functional status is poor, the predictive power of beliefs about severity is diminished. Analyses did not reveal moderation by either depression or oral functional status of the relationships between baseline beliefs about severity of illness and cigarette use at post-treatment, baseline beliefs about the utility of treatment and cigarette use at post-treatment, baseline beliefs about barriers to adherence and cigarette use at post-treatment, or baseline beliefs about barriers to adherence and alcohol use at follow-up.

Writing Intervention

The study had originally proposed a solution focused writing intervention to increase adherence. However, concerns were raised at MD Anderson Cancer Center about testing the new intervention with a population as ill as these patients. Therefore, the intervention was changed to a pilot study of the solution-focused writing. Ten percent of the sample would be asked to complete the intervention. In the end only 6 patients completed the task. Such data is presented next.

The intervention was administered about 3 weeks into the radiation treatment. Patients were asked to respond to 8 items written to start patients thinking about their oral care regimen, problems they were having, and possible solutions (see Appendix 2). There were no group differences between the writing condition and the rest of the sample with respect to illness perceptions, intent to adhere, actual adherence, or oral functional status. At baseline there were no differences with respect to depression. However, at both post-treatment and follow-up the 6 patients in the writing condition were significantly more depressed than the rest of the sample (see tables 52 and 53). Interestingly, depression scores were elevated for each of the six participants who completed the solution focused writing intervention.

Study condition		Baseline CESD	T2 CESD	T3 CESD
Questionnaire only	Mean	8.4390	11.7609	8.1463
	N	82	46	41
	Std. Deviation	9.21231	8.33516	9.87310
feedback	Mean	11.8333	23.3333	25.0000
	N	6	6	4
	Std. Deviation	13.12123	13.45610	23.40940
Total	Mean	8.6705	13.0962	9.6444
	N	88	52	45
	Std. Deviation	9.46830	9.64316	12.22731

Table 52. Means table comparing depression between writing condition and the rest of the sample at baseline, post treatment, and follow-up.

		Sum of Squares	df	Mean Square	F	Sig.
Baseline CESD	Between Groups	64.415	1	64.415	.716	.400
	Within Groups	7735.028	86	89.942		
	Total	7799.443	87			
T2 CESD	Between Groups	710.816	1	710.816	8.815	.005
	Within Groups	4031.703	50	80.634		
	Total	4742.519	51			
T3 CESD	Between Groups	1035.189	1	1035.189	8.030	.007
	Within Groups	5543.122	43	128.910		
	Total	6578.311	44			

Table 53. One-way ANOVA table comparing depression between writing condition and the rest of the sample at baseline, post treatment, and follow-up.

Writing Intervention Vignettes

The following is a sampling of the writing done by the six participants in the solution focused writing condition. These vignettes are included because they capture aspects of patients' thinking about their oral care that was not caught by the measures.

- "Fluoride treatments have been very hard due to gagging"
- "Dentist always seems backed up and running late. Maybe if his workload was not so heavy he could spend more time [with patients]"
- "[Most difficult has been] fluoride application because it is a life long commitment and I am unsure of the side effects of fluoride when some is swallowed"
- "I think more education on oral complications related to radiation therapy will help us ask for oral care sooner before serious complications develop"
- "[Most difficult has been to] brush teeth because people are thrown when you do it in public bathrooms or in parking lots"
- "It is not an easy task, but painful and downright uncomfortable. However, I realize I must cope with this since oral hygiene is very important towards my health and a speedy recovery"
- "Counseling prior to and during treatment would probably ease tension and reassure patients"
- "Routine and determination. Once the new oral care is part of my routine for a while it will become second nature to my daily routine. I am determined to keep my teeth and gums healthy"
- "Doctors can do a better job at discussing future problems if the oral care is not followed. This may help patients follow the routine"
- "The fluoride trays hurts your gums once you begin to get sores and blisters from the radiation"

CHAPTER 6: DISCUSSION

Overview of Findings

The present study examined the role of doctor-patient communication, patients' coping, and patients' illness related cognitions about cancer on treatment adherence to an oral health regimen among patients being treated for head and neck cancer. The oral health regimen encompassed three areas: adherence to a recommended oral care regimen, as well as patients' abilities to refrain from tobacco and alcohol use, as these present additional risks for complications and relapse.

The study was a longitudinal investigation of several factors that may influence patients' adherence to the oral health regimen. Refer to Figure 1 (page 59) for a graphic depiction of the proposed model. Doctor-patient interaction encompassed three aspects: instrumental information related to diagnosis, prognosis, and treatment; socio-emotional behaviors, which assesses physician's non-verbal behavior; and affective quality which is a measure of physician interpersonal skills. Patients' illness related conceptions incorporated two areas: beliefs about illness related factors such as diagnosis, prognosis, and vulnerability, and beliefs about treatment related factors such cost vs. benefit of treatment and treatment efficacy. Adherence was measured in three areas: adherence to the oral care program, smoking cessation, and abstinence from alcohol. Patients' coping style was also examined in terms of adaptive versus maladaptive coping strategies.

Several significant relationships emerged, particularly involving illness perceptions and adaptive coping; however, the data did not support the proposed integrative model. Significant findings will be further discussed below.

The Function of Doctor-Patient Communication

Three aspects of doctor-patient communication were examined: the first component encompasses what has been termed socio-emotional behaviors and taps physician behaviors such as verbal attentiveness, showing concerns, and negative talk. The second component has to do with the affective quality of the communication, i.e. is the doctor experienced as supportive, understanding, and caring by the patient. The last component is concerned with the kinds and clarity of information that is exchanged during the consultation.

Doctor-patient communication has been shown to play a role in patient adjustment to illness (Rutter, Iconomou, & Quine, 1996; Mager, & Andrykowski, 2002); however, findings from studies examining the role of doctor-patient communication with respect to quality of life have produced unclear results (Rutter, Iconomou, & Quine, 1996; Ong, Visser, Lammes, & de Haes, 2000), and little research to date has examined the role of doctor-patient communication on treatment adherence (Gilbar, 1989; Henman et al, 2002). This study aimed to examine the role of doctor-patient communication with respect to depression, oral functioning, illness perceptions, intent to adhere, and treatment adherence. Based on earlier research it was hypothesized that the more satisfied patients were with each component of the communication, the less depressed they would be, the fewer complications they would reports, the more optimistic, or realistic, their illness perceptions, the better their intent to adhere, and the more likely they would be to actually adhere.

As predicted, the instrumental quality of doctor-patient communication emerged as a significant predictor of beliefs about the utility of the oral care regimen at post-treatment

and also of intentions to adhere at follow-up. The more satisfied patients were with the instrumental quality of the consultation, the stronger the belief in the utility of the regimen (this might reflect better understanding of reasons for the regimen) and the better the intentions to adhere (again this might reflect better understanding of the consequences of non-adherence) (Manne, Markowitz, Winawer, Meropol, Haller, Rakowski, Babb, & Jandorf, 2002; Castellano, Wenger, and Graves, 2001; Husaini, Sherkat, Bragg, Levine, Emerson, Mentes, & Cain, 2001; Saidi, Sutton, & Bickler, 1998). However, unlike previous research (Gilbar, 1989; Henman et al, 2002) this study found no relationships between instrumental quality of the communication and actual adherence. The fact that the consequences of non-adherence are not immediate nor life threatening might explain this finding.

Consistent with hypotheses, the affective quality of doctor-patient communication emerged as a predictor of post-treatment oral functioning (Henman et al, 2002). That is, the less satisfied the patient was with the affective quality of the communication, the more discomfort they reported at post-treatment. Finally, the socio-emotional aspect of the communication was found to predict patients' belief about their susceptibility to future complications (Kucera, Lu, Raju, & Nathanson, 2002; Manne, Markowitz, Winawer, Meropol, Haller, Rakowski, Babb, & Jorf, 2002). That is, the more satisfied patients were with the physician's behavior at baseline, the less susceptible they believed they were at follow-up.

Results from previous studies that have examined the link between physician behavior and adherence have suggested that being satisfied with, and having high confidence in, one's physician is a good predictor of adherence (Gilbar, 1989, Henman et al, 2002).

However, the findings for doctor-patient communication in the present study did not support such research that exists on communication and adherence.

The Role of Coping

Research suggests that patients, who employ coping styles that can be characterized by involvement in medical decision making and a desire to understand and gain information about their illness, tend to better adjusted than those who do not, and are more likely to be proactive in their interactions with physicians (Keltikangas-Jaervinen, 1986; Ong, Visser, Van Zuuren, Rietbroek, Lammes, & de Haes, 1999). Whether these findings extend to treatment adherence is not known, and this question was part of the foundation of the present study. Based on previous research it was hypothesized that there would be a positive relationship between patients' adaptive coping and the variables in the model. That is, the more adaptive coping the better the less reported depression, the fewer oral complications reported, the better the intent to adhere, the better the adherence to oral care recommendations, the less tobacco and alcohol use, and the more optimistic the illness perceptions.

Integrative analyses revealed no significant relationships between adaptive coping and intent to adhere, oral care, tobacco use, or alcohol use. However adaptive coping was found to predict beliefs about susceptibility to future complications at follow-up. That is, the more adaptive coping, the less susceptible a patient believes he/she is to future oral complications. This finding is consistent with the hypothesis that adaptive coping would be related to a more optimistic outlook (Cohen, 2002; Arraras, Wright, Jusue, Tejedor, & Calvo, 2002). There was also a significant predictive relationship between adaptive

coping and beliefs about barriers to treatment at post-treatment. That is the more adaptive coping at baseline, the more barriers were perceived at post-treatment. This was in the opposite direction from what had been predicted (Stanton, Danoff-Burg, & Huggins, 1991). This finding might reflect a realistic appreciation of the lengths one will have to go to, to successfully adhere to oral care recommendations.

While previous research has linked choice of coping strategy with subjective reports of physical and psychological side effects during treatment with adjuvant chemotherapy among women with breast cancer (Spairo, Boggs, Rodrigue, Urry et all, 1997), research as yet has not found any links between coping and treatment adherence. The present study did not find any predictive relationship between coping and any of the outcome variables assessing adherence. Neither did coping play a role as a moderator between independent and dependent variables in the model. It appears that while coping strategy may play an important role in adjustment to illness, the function of coping in treatment adherence still warrants further investigation (Keltikangas-Jaervinen, 1986).

The Function of Illness Perceptions

Generally, research examining the effect of patients' beliefs about their illness and treatment has suggested that there may be a link to treatment adherence. Results from previous research (Matthews, Sellergren, Manfredi, & Williams, 2002) have suggested that the following components of illness perceptions may all be predictors of low treatment adherence: lack of knowledge about cancer and cancer treatment; beliefs about side effects; low expectations of treatment efficacy; poor understanding of causality, prognosis, and vulnerability; and a high cost/benefit ratio of treatment.

Illness perceptions, as measured in this study, encompass four different subscales: beliefs about utility of treatment, severity of illness, susceptibility to future complications or illness, and barriers to adherence. It was hypothesized that illness perceptions would be related to each downstream variable in the model: intent to adhere, oral care, tobacco use, and alcohol use (Matthews, Sellergren, Manfredi, & Williams, 2002; Siminoff & Fetting, 1991; Gilbar, 1989; Tamaroff, Festa, Adesman, & Walco, 1992; Horne & Weinman, 1999). While there were several significant correlations at different time points between three of the subscales (beliefs about utility, severity, and barriers) and intentions to adhere, there were no predictive relationships between illness perceptions and intent to adhere. However, beliefs about the severity of oral complications at baseline significantly predicted oral care at follow-up. Surprisingly this relationship was opposite from what was expected. That is, the more severe the complications were perceived to be, the less likely a patient was to follow the oral care recommendations.

One previous study (Siminoff & Fetting, 1991) also found that patients who believed that side effects of treatment would be likely and severe were significantly more likely to be non-compliant. It may be that patients who believed that oral complications would be severe also believed that there would be significant side effects and discomfort associated with the oral care regimen. Another possible explanation is that patients give up in the face of what is perceived to be a severe complication. Alternatively patients who correctly identify their illness as severe may suffer more treatment side effects, as a consequence of more prolonged and intense treatment, that in turn prevents adherence.

A similarly finding emerged for beliefs about the severity of illness, which were also found to be a significant predictor of cigarette use at post-treatment. That is, the more

severe the illness is perceived to be, the more the reported use of cigarettes. Beliefs about the utility of treatment also predicted cigarette use at post-treatment. Specifically, the higher the belief that treatment is useful, the more reported cigarette use. Again, this is an unexpected finding. Previous research has suggested the opposite relationship; that patients who reported low expectations of the treatment outcome (Gilbar, 1989) were significantly less likely to adhere to cancer treatment. Similar findings emerged from another study by Horne and Weinman (1999). Horne and Weinman (1999) found that patients who scored high in believing that the treatment was necessary were much more likely to be adherent, whereas having a high number of concerns about the treatment was correlated with lower reported adherence. It is unclear why patients in the present study reported lower adherence in the face of believing that treatment would be beneficial. It is possible that patients in this study believed that treatment was so powerful that it would cancel out the bad effects of smoking. Similarly, patients may have believed that while treatment would be of value, it was not necessary.

While not consistent with hypotheses (Schnoll, 2002; Vander, DiNardo, & Oliver, 1997; Ostroff et al, 1995), beliefs about barriers to adherence emerged as a significant negative predictor of post-treatment cigarette use. The more barriers were perceived at baseline, the less was the reported use of cigarettes at post-treatment. A similar relationship was found between beliefs about barriers to adherence and alcohol use at follow-up. That is, the more barriers were perceived at baseline, the less alcohol use was reported at follow-up. In other words, the more difficult the oral care regimen was perceived to be, the better patients did with respect to smoking and alcohol cessation. It is possible that rather than perceived difficulty leading to non-adherence due to patients

feeling overwhelmed by the oral care regimen, the perceived difficulty may have underscored the importance of following through with the regime.

To better understand this finding one might look to previous research, which has suggested that patients' illness perceptions are essential in creating the cognitive and psychological framework within which patients make treatment decision (Buick, 1997). A series of studies that attempted to link patients' illness-related cognitions to treatment adherence found that limited knowledge and misinformation about cancer and cancer treatment side effects tended to predict poor adherence to health related behaviors among cancer patients (Matthews, Sellergren, Manfredi, & Williams, 2002; Tamaroff, Festa, Adesman, & Walco, 1992), whereas being well-informed was associated with better adherence. These findings support the present results between perceived difficulty of the oral care regimen and adherence to smoking and alcohol cessation. That is, high perceived difficult might actually reflect a better understanding of the regimen, which *is* demanding, that then results in better adherence. Results from the cancer screening literature also support these findings. Knowledge about cancer (Friedman, Moore, Webb, & Puryear, 1999; Champion & Miller, 1996; Danigelis, Roberson, Worden, Flynn, et al, 1995; Beeker, Kraft, Southwell, & Jorgensen, 2000) and beliefs about the potential severity of cancer as well as one's perceived susceptibility to cancer are positively related to participation in screening (Lostao, Joiner, Pettit, Chorot, & S&in, 2001; Stark, Prince, Kucera, Lu, Raju, & Nathanson, 2002; Manne, Markowitz, Winawer, Meropol, Haller, Rakowski, Babb, & J&orf, 2002; Saidi, Sutton, & Bickler, 1998).

Similarly, results from studies examining beliefs about the value of cancer screening have indicated that patients who believe that the benefits (relief that one does not have

cancer) of screening outweigh the risks (finding out one has cancer) are significantly more likely to exhibit positive screening behaviors, as are those who believe that early detection might lead to a cure of their cancer (Husaini, Sherkat, Bragg, Levine, Emerson, Mentes, & Cain, 2001; Manne, Markowitz, Winawer, Meropol, Haller, Rakowski, Babb, & J&orf, 2002; Saidi, Sutton, & Bickler, 1998). Future studies in this area would do well in collecting information that specifically assessed what patients understood about their illness, treatment, and potential side effects.

Do Intentions to Adhere Matter?

There is little, if any, research examining the role of patients' intentions to adhere with respect to actual adherence and what previous research there is has lumped intentions to adhere in with illness perceptions (DiMatteo, et al, 1993). The present study examined intentions to adhere separately hypothesizing that other illness perceptions might shape a patient's intent to adhere, which in turn would predict actual adherence. As discussed earlier there were several significant correlations at across different time points between three of the subscales (beliefs about utility, severity, and barriers) and intentions to adhere, but no predictive relationships between illness perceptions and intent to adhere. This pattern of finding suggests that while there are correlations between baseline illness perceptions and post-treatment intentions to adhere, these relationships are not predictive in nature and some other variable(s) may be causing the observed correlations.

With respect to actual adherence it was hypothesized that baseline intent to adhere with doctors' recommendations would be positively related to actual adherence to each of the outcome variables (oral care, tobacco, use, and alcohol use) as well as self-reported

overall adherence (Weerdt, I. de,, Visser, A. P., Kok, G. & van der Veen, E. A.,1990; Farquharson, Noble, & Barker, 2004). In fact, there were no predictive relationships between intent to adhere and oral care at either post-treatment or follow-up, nor did intentions at post-treatment predict oral care at follow-up. No significant results were found with respect to the predictive value of intent to adhere on tobacco use or alcohol use at any time point. However, there was a significant predictive relationship between post-treatment intentions to adhere and follow-up self-reported adherence. That is, the better the intentions to adhere at post-treatment, the better the self-reported adherence at follow-up.

It is interesting to note that, contrary to predictions (Toljanic, Heshmati, & Bedard, 2002; Epstein, 1995), there was no relationship between patients' intentions to adhere and the actual decision to follow through with the recommended oral care regimen. It seems possible that factors during treatment, such as side effects from radiation treatment and possibly being focused on curative treatment rather than preventative treatment might explain the lack of any significant relationships between intentions to adhere and actual adherence. However, the fact that intentions to adhere do predict self-reported adherence suggests that intentions to adhere may not be predictive of actual adherence to recommendations, but rather predict patients' estimation of how well they are following their doctor's recommendation. This would be consistent with previous research, which has suggested that among patients the perspective on adherence is related to what the patient themselves consider a reasonable effort in the context of perceived constraints (Roberson, 1992).

The Role of Depression

Results from research examining the effect of co-morbid psychiatric disorders, cognitive impairment, interpersonal dysfunction, and addiction in relation to treatment adherence (Kunkel, Woods, Rodgers, & Myers, 1997; Seddon, Zabora, & Smith, 1992; Goldberg, 1983) have suggested that both psychological and psychiatric complaints are linked with poor adherence. Therefore, depression was examined in relation to each of the variables in the model.

As hypothesized baseline (Kunkel, Woods, Rodgers, & Myers, 1997; Seddon, Zabora, & Smith, 1992; Goldberg, 1983) depression did emerge as a significant predictor of illness perceptions. However, there was only one such predictive relationship: baseline depression predicted post-treatment beliefs about susceptibility. The less depression at baseline, the more susceptible the patient believed he/she was to future complications at post-treatment. This is a rather unexpected finding as it had been predicted that less depression would lead to more optimistic beliefs about potential oral complications (Ayres, Hoon, Franzoni, Matheny, et al, 1994). It might be that the presence of depressive symptoms lowers the threshold of what the patient can cope with. As a consequence the importance of the oral care regimen and the potential for oral complications may be perceived as secondary to the cancer treatment and in the context of acute illness be suppressed, or avoided, until the patients is feeling less overwhelmed and better able to cope with additional demands. If so, this would explain the ability of less depressed patients to better cope with the information as is. It would also be consistent with the literature linking depression and maladaptive, or avoidant, coping (Carver, C. S. et al, 1993; Lazarus, R. S., & Folkman, S., 1984). Another point to

consider is that though it was hypothesized that less depression would lead to more optimistic illness perceptions, it would actually be more adaptive for patients, in the long run, to assimilate the true significance of the potential complications they are at risk for and not deceive themselves into believing that consequences of non-adherence are benign.

As hypothesized, post-treatment depression was found to predict follow-up intentions to adhere (Ayres, Hoon, Franzoni, Matheny, et al, 1994; Seddon, Zabora, & Smith, 1992; Goldberg, 1983). That is, the more depressed at post-treatment, the lower the intent to adhere at follow-up. If it is assumed that intent to adhere is associated with actual adherence, then this finding is consistent with previous research, which has suggested that poor psychosocial adjustment is a predictor of non-adherence (Kunkel, Woods, Rodgers, & Myers, 1997; Seddon, Zabora, & Smith, 1992; Goldberg, 1983; Gilbar 1989). However, contrary to predictions, there were no predictive relationships between depression and oral care, tobacco use, and alcohol use. That is, depression did not predict actual adherence. Interestingly, the lack of findings with respect to adherence is consistent with one study examining the role of psychiatric complaints on treatment adherence among patients with head and neck cancer (Girardi, de Pisa, Cianfriglia, Perrino, et al, 1992). Results from this previous study indicated that neither somatic disturbance, anxiety, insomnia, social dysfunction, nor depression predicted treatment adherence.

The Effects of Oral Functional Status

Research examining adherence to oral care among head and neck cancer patients has found that many patients have difficulty following the oral care recommendations made (Lockhart and Clark, 1994; Toljanic, Heshmati, & Bedard, 2002). It was hypothesized that one of the reasons for this might be that the radiation therapy these patients undergo often exacerbates oral discomfort and pain, making it painful and uncomfortable to brush, floss, and apply fluoride.

While oral functioning did not predict depression, coping, oral care, tobacco use, alcohol use, or overall self-reported adherence at post-treatment or follow-up, there were several significant predictive relationships between oral functional status and doctor-patient communication, illness perceptions, and intent to adhere. A predictive relationship emerged between oral functioning and the affective quality of doctor-patient communication at post-treatment, with the affective quality of doctor-patient communication predicting post-treatment oral functioning. That is, the less satisfied patients were with the affective quality of the communication, the more discomfort they reported at post-treatment.

With respect to illness perceptions oral functioning at baseline emerged as a significant predictor of beliefs about susceptibility to future oral complications. That is, the fewer oral complications at baseline, the stronger the belief that one would be likely to suffer oral complications in the future. This relationship was also significant at follow-up. This finding is contrary to expectations that a low number or oral complications would lead a person to expect fewer oral complications in the future. It is possible that patients may have been told to expect oral complications by their doctor, and that the finding reflects

the belief that if one has few, or no, complications at baseline, the expectation is that these will soon develop.

At post-treatment oral functioning predicted follow-up beliefs about utility of treatment. Specifically, the ($\beta = .401$, $p < 0.01$), susceptibility to future complications ($\beta = -.549$, $p < 0.01$), and barriers to adherence ($\beta = .352$, $p < 0.05$).

Post-treatment oral functional status also predicted follow-up intentions to adhere ($\beta = -.561$, $p < 0.01$). That is, the more complications at post-treatment, the less the intent to adhere at follow-up.

Moreover, contrary to what had been expected (Tavss, 1997; Kennedy & Erb, 2002), there were no predictive relationships between oral functioning and oral care, tobacco use, alcohol use, or overall self-reported adherence at any time point. It had been hypothesized that patients who reported a high number of oral complications would have more difficulty following the oral care regimen. In contrast, the present results indicate that oral functional status does not play a role in patients' decision to adhere to the oral care regimen. Given the extent of side effects to the mouth and throat, that at times necessitate a feeding tube, the lack of findings is surprising. However, some interesting findings from previous research suggest that while treatment side effects have been shown to be predictors of non-adherence in other illnesses, side effects of cancer treatment, though highly adverse, do not predict adherence among cancer patients (Richardson, Marks, & Levine, 1988; O'Connor, Boyd, Warde, Stolbach, & Till, 1987). It would be interesting to further examine patients' beliefs about the oral care regimen to find out if they perceive it as part of their cancer treatment or as a separate treatment all together. One other possible explanation is that some patients in the sample were also

enrolled in a clinical trial of the drug Amifostine (Bensadoun, Schubert, Lalla, & Keefe, 2006). The drug was administered by injection prior to each radiation treatment and was being investigated for it's purportedly protective qualities against the development of oral and pharyngeal side effects associated with radiation. This may have lowered the number of patients experiencing severe side effects from radiation that would otherwise have made adherence to oral care difficult. Unfortunately, data analyses were not able to control for this factor and examine the adherence rates of patients on the Amifostine trial versus those who were not part of the trial.

Finally, with respect to oral functional status at baseline, there was a group difference for cancer site. Specifically, patients with oral cancer reported significantly more problems than those with oralpharyngeal cancer at baseline, but not at post-treatment or follow-up. As the measure assessing oral functional status includes items for both the oral cavity and the throat, it is difficult to explain this finding unless having a cancer in one's mouth is somehow more uncomfortable that having a cancer in one's throat.

Moderation by Oral Functional Status

Exploratory questions investigated whether depression and functional status might moderate the relationships between a) patients' perceptions of doctor-patient communication and patient adherence, b) patients' coping and patient adherence, and c) patients' illness perceptions and patient adherence. In accordance with Baron and Kenney's (1986) stipulations for moderation that there be a significant regression between the dependent and independent variable, each set of variables were tested to see if this relationship was indeed present. Analyses did not reveal any significant predictive

relationships doctor-patient communication or adherence nor between coping and adherence. However, there were significant predictive relationships between illness perceptions and adherence. Integrative analyses revealed that by oral functional status moderated the relationship between baseline beliefs about the severity of illness and actual oral care at post-treatment. That is, when oral functional status was good, beliefs about severity of illness were good predictors of adherence. In contrast, when oral functional status was poor, the predictive power of beliefs about severity diminished. In other words, the severity of oral side effects from radiation treatment might make the oral care regimen so uncomfortable and painful that even though the patient believes the complications are severe they still choose to not, or are not able to, follow recommendations.

Limitations of the Study

Results from the current study failed to support the proposed integrative model. There are several factors that deserve consideration when attempting to understand why the model did not work. First, the study assumed that patients would be invested in following oral care recommendations, but failed to take into account that the oral care regimen may not have been considered of much importance in the context of treatment aimed directly at curing one's cancer. Second, radiation side effects cause burning and thinning of the mucosa in the mouth and throat, which may have made adherence to the oral care regimen extremely painful not only for the duration of treatment, but also at post-treatment and follow-up, as healing occurs only slowly.

Another fact that should be taking into consideration is, that while the measure was anchored on the dental oncologist, each patient saw their radiation oncologist on a weekly basis and worked closely with him/her throughout their radiation treatment, whereas they saw their dental oncologist once prior to treatment, and then again post-treatment. The radiation oncologist reinforced oral care issues as well and had the measured been anchored on him/her results might have been different. In other words, it may be important, when considering the doctor-patient relationship in the research setting, that we ask the patient which doctor he/she considers their *primary* doctor in the cancer team.

The cancer screening literature emphasizes the importance of this point. Two of the strongest predictors of participation in cancer screening are related to the primary medical provider. First, having a consistent source of care, such as a family physician or primary care physician who is seen on a regular basis, significantly predicts compliance with cancer screening (Mandelblatt, Gold, O'Malley, Taylor, Cagney, Hopkins, and Kerner, 1999; Zambrana, Breen, Fox, and Gutierrez-Mohamed, 1999). Further, patients whose physician specifically recommend and encourage cancer screening procedures are significantly more likely to comply with screening behaviors than those whose physician do not specify such procedures (Manne, Markowitz, Winawer, Meropol, Haller, Rakowski, Babb, and Jandorf, 2002; Castellano, Wenger, and Graves, 2001; Friedman, Moore, Webb, and Puryear, 1999; Champion and Miller, 1996; Costanza, Stoddard, Gaw, and Zapka, 1992; Allen, Sorensen, Stoddard, Peterson, and Colditz, 1999).

A possible explanation may also be found in a model proposed by Lepper, Martin, and DiMatteo (1995), which pertains to the nonverbal exchange between patients and physicians and is based on the expectations for patient involvement on behalf of both

patients and physicians. Authors suggest that high patient treatment adherence is most likely in situations where both patient and physician expect patient involvement. This study did not assess such expectations on behalf of patients or physicians.

Yet another thing that should be taken into consideration concerns measurement. Because was no existing measure of oral care at the time of the study a measure was created, consisting of face valid items asking patients to record the extend to which they were able to follow the specific oral care recommendations (See Appendix 1, page 197). Internal consistency was moderate, an indication that the measure may not have adequately assessed adherence, or at the very least that it might be productive to repeat analyses looking at each individual behavior separately. Another study is currently being conducted at MDACC collecting more information about this measure.

There may also have been limitations associated with the measures chosen for tobacco and alcohol use. It is possible that there were too many questions asked, when fewer would have sufficed. This may explain why many patients chose to answer the questionnaires by drawing a line across the page to indicate that they did not use tobacco or alcohol over the past month. Unfortunately, for coding purposes, such data was considered 'lost' and coded as 'missing' which resulted in significant missing data on these outcome measures.

Missing data presented a problem as pertaining to statistical power. First of all, a number of patients felt too sick at post-treatment to fill out the 18-page questionnaire. Secondly, at follow-up patients often came in, for one day, from out of town. This meant that, if the patient was not contacted during their appointment, data collection had to rely on mailing the questionnaire out. Only about 50% of patients who received a

questionnaire by mail returned it. This resulted in a very low N for the outcome variables at both post-treatment and follow-up, and a possibly skewed sample with those completing the questionnaire sharing some sort of characteristic not present in the rest of the sample.

Last, but not least, the sample in this study is hardly representative. This sample was primarily Caucasian, male, married, middle aged to older, highly educated, and had a household income well above average. Previous research has found age, marital status, level of education, and racial background are all predictors of cancer screening behavior. Such studies have found an interesting correlation between age and adherence to screening recommendations. Generally, being older, greater than 50 years of age, is a positive predictor of screening adherence (Zambrana, Breen, Fox, & Gutierrez-Mohamed, 1999; Husaini, Sherkat, Bragg, Levine, Emerson, Mentes, & Cain, 2001; Champion & Miller, 1996; Rimer, Conaway, Lyna, Rakowski, William, et al, 1996). However, some studies have found that women above age 65 are significantly less likely to comply with cancer screening than their younger counterparts. (Mandelblatt, Gold, O'Malley, Taylor, Cagney, Hopkins, & Kerner, 1999; Rawl, Champion, Menon, & Foster, 2000). This non-linear relationship between age and screening behavior is of particular interest as the risk of developing cancer increases with age. It is unclear whether this relationship is true for males as well. Marital status and education are other indicators of screening adherence. Studies have found that being married increase adherence to recommended cancer screening, as does having a higher level of education (Zambrana, Breen, Fox, & Gutierrez-Mohamed, 1999; Amonkar, & Madhavan, 2002; Franco, Belinson, Casey, Plummer, Tamburrino, & Tung, 2000; Friedman, Moore, Webb, & Puryear, 1999; Rimer,

Conaway, Lyna, Rakowski, William, et al, 1996). However, cancer-screening adherence is significantly lower among minority groups (Rawl, Champion, Menon, & Foster, 2000; Rojas, Mandelblatt, Cagney, Kerner, & Freeman, 1996).

All in all it would be expected that the current sample would be highly adherent. The fact that the findings of this study did not support this expectation suggests that some other, unmeasured variable, interferes with adherence, or at least the measurement of adherence. Certainly the vignettes from the six participants in the solution-focused writing condition suggests that patients were struggling with the oral care regimen to a higher degree than the data gathered through questionnaires indicated. The writings also speaks to aspects of following the oral care regimen that the present study did not take into consideration such as awkwardness when performing oral care in public as well as having to tote around a toothbrush, toothpaste, and floss. Finally, the possibility that the importance of the oral care regimen is overshadowed by the active cancer treatment phase was not assessed in the present study.

Practical Applications of Findings

The Role of the Interpersonal Environment

Doctor-patient communication was found to be a significant predictor of beliefs about the utility of the oral care regimen and of intentions to adhere. Specifically, the more satisfied patients were with the instrumental quality of the consultation, the stronger the belief in the utility of the regimen and the better the intentions to adhere. These findings suggest that the amount of information the doctor provides, the format in which the information is delivered, and the amount of time allotted to the patient for asking

questions all play an important role in patient understanding of the treatment regimen and that this understanding leads to stronger beliefs in the utility of the recommended treatment. Thus, it is both in our own and our patients' interest that we create an interpersonal environment that will facilitate such understanding.

The affective quality of doctor-patient communication emerged as a predictor of post-treatment oral functioning. That is, the less satisfied patients were with the affective quality of the communication, the more discomfort they reported at post-treatment. This finding is consistent with previous research, which has found that low satisfaction with the affective quality of the doctor-patient communication leads to poorer adjustment, which in turn has been linked with a higher number of reported side effects ((Rutter, Iconomou, & Quine, 1996; Mager, & Andrykowski, 2002; Thuné-Boyle, Myers, & Newman, 2006; Alder & Bitzer, 2003). This relationship underscores the importance of creating an environment in which the patient feels supported, safe, and cared for by his/her doctor. Such an atmosphere produces a framework within which the patient can assimilate information, cope with the implications of his/her illness, and go on to make the necessary adjustments.

Lastly, the socio-emotional aspect of the communication was found to predict patients' belief about their susceptibility to future complications. The more satisfied patients were with the physician's behavior at baseline, the more susceptible they believed they were at follow-up. It was speculated that positive behaviors on behalf of the physician might create a safe environment that allow patients to let down their defense and take the information provided more seriously. If this is so, then this finding is consistent with other findings for doctor-patient communication, which have found that patients report

positive experiences when consultations that were characterized by an affective communication style, a comprehensive patient-centered approach and the promotion of a working relationship (McWilliam, Brown, & Stewart, 2000; Ong, Visser, Lammes, & de Haes, 2000; Hebert, Jenckes, Ford, O'Connor, & Cooper, 2001). This is an important finding because it illustrates that satisfaction with physician behavior does not necessarily lead a patient to have a positive outlook, but rather supports the patient in facing the reality of his/her illness, which will ultimately allow the patient to make appropriate decisions with respect to treatment. Another implication is that, the fear that giving bad news will comprise the positive relationship doctors have with their patients may be unfounded. If the information is given in an environment that is perceived as caring and supportive by the patients, the patients are not only is better able to face the bad news, they are still very satisfied with their doctors.

Implications for Coping

While analyses revealed no significant relationships between adaptive coping and intent to adhere, oral care, tobacco use, or alcohol use, adaptive coping was found to predict beliefs about susceptibility to future complications at follow-up. That is, the more adaptive coping, the less susceptible a patient believes he/she is to future oral complications. This finding is consistent with the hypothesis that adaptive coping would lead to a more optimistic outlook. There is, of course, always a fine line between the utility of adaptive coping and the extent to which adaptive coping might lead someone to view circumstances in a more positive way than is warranted. That is, while we want to

foster adaptive coping in our patients we also want to make sure they are realistic about their diagnosis and treatment, so that they can make reasonable decisions.

There was also a significant predictive relationship between adaptive coping and beliefs about barriers to treatment at post-treatment. That is the more adaptive coping at baseline, the more barriers were perceived at post-treatment. This was in the opposite direction from what had been predicted. It was speculated that this finding might reflect a pragmatic appreciation of the lengths one will have to go to, to successfully adhere to oral care recommendations. In other words, it may be of value to assess patients' coping strategies to help guide them in their ability to set sensible expectations with respect to their diagnosis, prognosis, and treatment as these influence medical decision making.

Implications of Illness Perceptions

Beliefs about the severity of oral complications at baseline significantly predicted oral care at follow-up. That is, the more severe the complications were perceived to be, the less likely a patient was to follow the oral care recommendations. It was speculated that patients might give up in the face of what is perceived to be a severe complication, or that maybe patients who correctly identify their illness as severe suffer more treatment side effects, as a consequence of more prolonged and intense treatment, that in turn prevent adherence. The finding emphasizes the importance of assessing patients' own understanding of their diagnosis, prognosis, and treatment, as such perceptions can influence treatment decisions. The focus of the consultation would then shift from a strict emphasis that the patient adhere to recommendations under all circumstances to working with the patient to overcome misunderstandings, or misgivings, and, when needed, to

work with the patient to reach a compromise that still allows the patient to get as much as possible out of the treatment. This might seem like a radical shift from traditional medicine, but if the alternative is complete non-adherence, then meeting the patient where he/she is and creating a cooperative relationship that allows the patient to receive at least part of their treatment could present a satisfactory goal for both partners.

A similarly finding emerged for beliefs about the severity of illness, which were also found to be a significant predictor of cigarette use at post-treatment. That is, the more severe the illness was perceived to be, the higher was the reported use of cigarettes. Beliefs about the utility of treatment also predicted cigarette use at post-treatment. Specifically, the higher the belief that treatment is useful, the more reported cigarette use. This finding suggests that believing a particular treatment will be useful is not necessarily predictive of actually engaging in the treatment. It implies that a patient may understand what a treatment entails and agree that the treatment is likely to be of benefit, but still decide to not follow through with it. The finding also highlights the importance of not assuming that, just because the patient expresses understanding and agreement, the patient will adhere. In other words, as providers we may have to inquire to our patients' intentions and plans and engage in problem solving strategies to address concerns and reluctance on behalf of the patient to better promote adherence to treatment recommendations.

While not consistent with hypotheses, beliefs about barriers to adherence emerged as a significant negative predictor of post-treatment cigarette use. The more barriers were perceived at baseline, the less was the reported use of cigarettes at post-treatment. A similar relationship was found between beliefs about barriers to adherence and alcohol

use at follow-up. That is, the more barriers were perceived at baseline, the less alcohol use was reported at follow-up. In other words, the more difficult the oral care regimen was perceived to be, the better patients did with respect to smoking and alcohol cessation. It was speculated that rather than perceived difficulty leading to non-adherence due to patients feeling overwhelmed by the oral care regimen, the perceived difficulty may have underscored the importance of following through with the regime. This finding supports honesty and clarity when informing patients about treatment. While the treatment might be perceived as difficult, these data makes the case that patients are able to handle it. It also hints at some of the thinking that might be going on in patients: While the regimen as a whole is perceived to be difficult, it may be that in contrast to other treatment requirements quitting tobacco and alcohol is thought to be relatively easy. Again, this suggests that patients try to do as much as they feel they are able to do within the current context even if it does not meet what we, as providers, would consider ideal.

Applications of Intent to Adhere

There was a significant predictive relationship between post-treatment intentions to adhere and follow-up self-reported adherence. That is, the better the intentions to adhere were at post-treatment, the better the self-reported adherence was at follow-up. However, intentions to adhere does not predict actual adherence. The finding suggests that patients' intentions to adhere predict patients' own assessment of how well they are doing with respect to the oral care regimen, but not their actual adherence. This is consistent with other findings in this present study, which have suggested that there is a discrepancy between what patients feel is adequate or feasible versus what we, as

providers, would like to see with respect to treatment adherence. It also emphasizes the point that if we want a picture of how well our patients are actually doing we need to ask specific questions related to adherence behaviors, rather than asking patients for their own global sense of how they are doing. Finally, this finding suggests that something happens between a patient's good intentions to adhere and actual adherence. Maybe recommendations are harder to carry out than anticipated or perhaps other treatment related effects get in the way. As providers we might do well in continuously assessing how patients are doing with respect to adherence and be prepared to problem solve as things come up.

Implications for Depression

Baseline depression was found to predict post-treatment beliefs about susceptibility so that the less depression reported at baseline, the more susceptible the patient believed he/she was to future complications at post-treatment. This was a rather unexpected finding as it had been predicted that less depression would lead to more optimistic beliefs about potential oral complications. The finding suggests that the absence of depressive symptoms do not preclude the presence of negative illness perceptions. Practically this can be translated into remembering that while there is certainly value in screening patients for depression, we should not forget that patients who are not reporting depression might still have negative cognitions surrounding their cancer diagnosis and treatment.

Post-treatment depression was found to predict follow-up intentions to adhere. That is, the more depressed a patient was at post-treatment, the lower the patient's intent to adhere at follow-up. These results are consistent with previous research, which has

suggested that poor psychosocial adjustment is a predictor of non-adherence (Ayres, Hoon, Franzoni, Matheny, et al, 1994; Gilbar, 1989). The finding underscores the importance of a holistic approach to patient care in the medical setting. It is well known that depression and other psychiatric disorders can interfere with patients' ability to cope with and adjust to a new diagnosis, and that such patients struggle more when it comes to treatment adherence than do those who are not such afflicted. This point highlights the importance of continued screening and assessment of depression among the medically ill.

Practical Issues Related to Oral Functioning

Oral functioning at baseline emerged as a significant predictor of beliefs about the utility of treatment at post-treatment. That is, the more oral complications reported at baseline, the weaker the belief in the utility of the oral care regimen was at post-treatment. This relationship was not significant at follow-up. It makes sense that a patient who is already suffering from significant complications at baseline is less likely to see the utility of carrying out the oral care regimen. In this instance, support from the primary provider might be important to help the patient understand the long-range goals of the oral care regimen, and to provide encouragement that the complications will diminish after treatment has ended. This may be another situation that calls for a compromise with respect to the extent that the patient is able to follow the oral care regimen until oral discomfort abates.

A significant predictive relationship emerged between baseline oral functional status and post-treatment intent to adhere. Specifically, the more complications were reported at baseline the less the intent to adhere was at post-treatment. This association was not

found at follow-up. The observed relationship is properly a function of the number of radiation related side effects patients experience during treatment. If side effects are severe it is understandable that patients are less likely to plan future adherence to an oral care regimen that may well exacerbate oral and pharyngeal discomfort and pain. Again, together the physician and the patient will need to negotiate which parts of the oral care regimen the patient will be able and willing to do until treatment side effects subside.

Interestingly, there was a group difference with respect to oral functional status at baseline. Specifically, patients with oral cancer reported significantly more problems than those with oralpharyngeal cancer at baseline, but not at post-treatment or follow-up. Given the above finding, this suggests that patients with oral cancer might be at greater risk for non-adherence to the oral care regimen or, at least, that their intentions to adhere will be low. If this finding turns out to be consistent in future research then a special intervention aimed at those patients with oral cancers might be in order to help them better manage their oral health during treatment.

Finally, analyses found that oral functional status moderated the relationship between baseline beliefs about the severity of illness and actual adherence. That is, when oral functional status was good, beliefs about severity of illness were good predictors of adherence, whereas when oral functional status was poor, the predictive power of beliefs about severity was diminished. In other words, the severity of oral side effects from radiation treatment might make the oral care regimen so uncomfortable and painful that even though the patient believes the complications are severe they still choose to not, or are not able to, follow recommendations.

This finding underscores the role of treatment related side effects on treatment adherence. Basically, when side effects get severe other predictive variables fall by the wayside and the patient may become non-adherent until such side effects have been resolved. Again, these results suggest that monitoring oral and oralpharyngeal discomfort and pain will be important so that efforts to ease those can be initiated and a modified oral care regimen can be implemented allowing patients to do as much as they can with respect to oral care. As providers we can encourage patients that even if the can only tolerate parts of the oral care regimen, this is still better than doing nothing at all.

Future Directions

Cleary more research is needed to better understand the factors that lead head and neck cancer patients to adhere, or not adhere, to recommendation for oral care, smoking cessation, and alcohol cessation. While the present study found some interesting relationships, research in this area is still searching for an integrative model explaining treatment adherence.

Areas for future study on treatment adherence include the incorporation of models on medical decision-making. Such research might consider the kinds of information patients use when making a decision to adhere to a specific treatment, and how one's ability to actually adhere provides feedback that might change the original decision. Such models ought also to continue to broaden out understanding of the concept of adherence. From a medical point of view the parameters of adherence are often clearly defined in terms of a patient following a prescribed treatment regimen. However, as findings from the present study suggests that patients define adherence differently. In the medical literature

treatment adherence has been defined as "the degree to which a patient 'voluntarily' follows the (treatment) regimen recommended by a (health care) provider" (Barofsky, 1984). Inherent in this definition is the point that treatment adherence involves *both* the health care provider and the patient. Interestingly, most measures of treatment adherence fail to incorporate adherence as it is understood by the patients themselves. For example, previous research among chronically ill patients has found that these patients describe adherence as 'doing one's best' under the circumstances (Roberson, 1992). Further, these patients often defined adherence in the context of their life (i.e. actual ability to follow through with recommendations) as well as their perception of what is reasonable and effective (Roberson, 1992). Future research should aim to incorporate patients views of adherence in our effort to better understand what leads patient to follow a recommended treatment and how to improve adherence in way that makes sense to patients.

An additional important factor that the current study did not examine is the role of family, or social, support. Research from the cancer-screening literature has found that psychosocial predictors of compliance encompass social support (Husaini, Sherkat, Bragg, Levine, Emerson, Mentes, and Cain, 2001; Manne, Markowitz, Winawer, Meropol, Haller, Rakowski, Babb, and Jandorf, 2002) and the perception that one's health status matters to others (Danigelis, Roberson, Worden, Flynn, et al, 1995). That is, not only does it appears to be important have support from others that getting screened for cancer is the right thing to do; the support attained through the feeling that someone cares about one's health increases the likelihood of adherence to screening recommendations. It is entirely feasible that social support may play a role in adherence to treatment as well, in particular when the treatment is unpleasant or time consuming. Another aspect of

social support to consider is the impact of the illness on the healthy spouse. Spouses of patients in the present study were often observed expressing much more distress in response to the cancer diagnosis and cancer treatment than patients themselves. It is conceivable that the distress the spouse experience might influence the dynamics between the patient and the spouse in a less than constructive manner.

When discussing the change of health behaviors it is difficult to not briefly mention Prochaska and DiClemente's (1992) stages of change model. The model proposes five stages of change: pre-contemplation, contemplation, preparation, action, and maintenance. Based on the model it is suggested that actual behavior change does not take place until at person is in the action stage. Adherence to the oral care regimen among head and neck cancer patients is a lifelong commitment that represents a drastic change for most patients. For many, this requires a radical transformation in how they think about their oral care. What was enough before is no longer adequate. Integration and implementation of such change most likely does not happen overnight, and gaining a sense of where patients are in their readiness to change is integral to understanding their level of adherence.

APPENDIX 1:
Measures

Demographic information
(Baseline only)

1. What is your date of birth (mm/dd/yy)? _____

2. What is your current age? _____

3. Sex
    1. male
    2. female

4. What is your ethnic background?
    1. Caucasian (white)
    2. African American
    3. Asian, Pacific Islander
    4. American Indian
    5. Hispanic
    6. Other _____

5. What is your current marital status?
    1. Never married
    2. Married
    3. Divorced or separated
    4. Widowed
    5. Other _____

6. Are you currently:
    1. employed for wages, full-time
    2. employed for wages, part-time
    3. Self-employed
    4. Out of work for more than 1 year
    5. Out of work for less than 1 year
    6. Homemaker
    7. Student
    8. Retired
    9. Disabled and unable to work

7. What is the highest grade or year of school you completed?
    1. Eight grade or less
    2. Some high school
    3. High school or GED certificate
    4. Some college
    5. College graduate
    6. Post graduate or professional degree

8. Which of the following categories best describes your annual income from all sources?

1. Less than $5,000
2. $5,000 to $9,999
3. $10,000 to $14,999
4. $15,000 to $19,999
5. $20,000 to $24,999
6. $25,000 to $34,999
7. $35,000 to $49,999
8. $50,000 to 74,999
9. $75,000 or more

9. Do you belong to a church, temple, or other religious group

1. Yes
2. No

10. What is your religious preference?

1. Catholic
2. Protestant
3. Jewish
4. Other. Please specify _____
5. None

11. How strong would you say your religious or spiritual faith is?

1. Very strong
2. Moderate
3. Somewhat
4. Not at all

Health information

Smoking (cigarettes and/or pipe tobacco)

1. Have you smoked at least 100 cigarettes (5 packs) in your entire life?
    1. Yes
    2. No (if the answer is "no" go to question 6 on the next page)
    3. Don't know/Not sure

2. Do you <u>now</u> smoke cigarettes everyday, some days, or not at all?
    1. Everyday
    2. Some days
    3. Not at all

3. On the average, about how many cigarettes a day do you now smoke? (1 pack =20)
    1. Number of cigarettes _____/Day
    2. Don't know/Not sure

4. During the past 12 months, have you quit smoking for 1 day or longer?
    1. Yes
    2. No
    3. Don't know/Not sure

5. About how long has it been since you last smoked cigarettes regularly, that is, daily?
    1. Within the past week (0 to 7 days ago)
    2. Within the past month (0 to 1 month ago)
    3. Within the past 3 months (1 to 3 months ago)
    4. Within the past 6 months (3 to 6 months ago)
    5. Within the past year (6 to 12 months ago)
    6. Within the past 5 years (1 to 5 years ago)
    7. Within the past 15 years (5 to 15 years ago)
    8. 15 or more years ago
    9. Don't know/Not sure
    10. Never smoked regularly

Smokeless Tobacco

6. Have you ever used or tried any smokeless tobacco product such as chewing tobacco or snuff?

1. yes, chewing tobacco
2. yes, snuff
3. yes, both chewing tobacco and snuff
4. no (skip to question 12 on the next page)

7. Do you currently use any smokeless tobacco product, such as chewing tobacco or snuff?

1. yes, chewing tobacco
2. yes, snuff
3. yes, both chewing tobacco and snuff
4. no (skip to question 12 on the next page)

8. How often do you now use the smokeless tobacco product you indicated above?

1. Every day
2. Some days

9. On the days that you use the smokeless tobacco product you indicated above, how many times a day to use it?

1. Number of chews/snuffs _____/Day
2. Don't know/not sure

10. During the past 12 months, have you quit using smokeless tobacco for 1 day or longer?

1. Yes
2. No
3. Don't know/Not sure

11. About how long has it been since you last used smokeless tobacco regularly, that is, daily?

1. Within the past week (0 to 7 days ago)
2. Within the past month (0 to 1 month ago)
3. Within the past 3 months (1 to 3 months ago)
4. Within the past 6 months (3 to 6 months ago)
5. Within the past year (6 to 12 months ago)
6. Within the past 5 years (1 to 5 years ago)
7. Within the past 15 years (5 to 15 years ago)
8. 15 or more years ago
9. Don't know/Not sure
10. Never smoked regularly

Alcohol Use

12. During the past month, have you had at least one drink of any alcoholic beverage such as beer, wine, wine coolers, or liquor?

1. Yes
2. No (if the answer is "no" go to question 1 on page 6)
3. Don't know/Not sure

13. During the past month, how many days per month did you drink any alcoholic beverages, on the average?

1._____Days per month
2._____Don't know/Not sure

14. On the days when you drank, about how many drinks did you drink on the average?
(A drink is 1 can or bottle of beer, 1 glass of wine, 1 can or bottle of wine cooler, 1 cocktail, or 1 shot of liquor)

1. Number of drinks _____
2. Don't know/Not sure

15. Considering all types of alcoholic beverages, how many times during the past month did you have 5 or more drinks on an occasion?

1. Number of times _____
2. Never
3. Don't know/Not sure

Oral health
(Baseline version)

1. How long has it been since you last visited a dentist or a dental clinic for any reason?
    1. Within the past year (1 to 12 months ago)
    2. Within the past 2 years (1 to 2 years ago)
    3. Within the past 5 years (2 to 5 years ago)
    4. 5 or more years ago
    5. Don't know/Not sure
    6. Never

2. How many of your permanent teeth have been removed because of tooth decay or gum disease? Do not include teeth lost for other reasons, such as injury or orthodontics.
    1. 5 or fewer
    2. 6 or more but not all
    3. All
    4. None
    5. Don't know/Not sure

3. How long has it been since you had your teeth "cleaned" by a dentist or dental hygienist?
    1. Within the past year (1 to 12 months ago)
    2. Within the past 2 years (1 to 2 years ago)
    3. Within the past 5 years (2 to 5 years ago)
    4. 5 or more years ago
    5. Don't know/Not sure
    6. Never

4. During the past week, how often did you brush your teeth?
    1. I never brushed my teeth (skip to question #6 on the next page)
    2. 1-2 days
    3. 3-4 days
    4. 5 days
    5. 6 days
    6. daily

5. In general, on the days when you brushed your teeth, how many times did you brush?
    1. I brushed once a day
    2. I brushed 2 times a day
    3. I brushed 3 times a day
    4. I brushed 4 times a day or more

6. During the past week, how often did you floss your teeth?

1. I never flossed my teeth (skip to question #7)
2. 1-2 days
3. 3-4 days
4. 5 days
5. 6 days
6. daily

7. In general, on the days when you flossed your teeth, how many times did you floss?

1. I flossed once a day
2. I flossed 2 times a day
3. I flossed 3 times a day
4. I flossed 4 times a day or more

8. Do you practice other dental care on a regular basis other than describe above, such as the use of mouth rinse and fluoride applications?

1. Yes
2. No

If yes, please describe: _____

Oral health
(Follow-up version)

Questions about your oral health

We are interested in learning more about how patients manage their oral health. Thinking back on the past week, please answer each of the questions below. Please be as honest as possible. Your answers will remain strictly confidential and your doctor will not see them.

1. During the past week, was there ever a day when you completely skipped brushing your teeth? (please circle one answer)

a. no (go to question #3)
b. yes

2. Below you will see a line for each day of the week. On the days that you that you skipped brushing your teeth, please tell us briefly the reason why you did not brush. (Some examples are: forgetting, feeling too tired, did not bring tooth brush or tooth paste, gums too sore, having difficulty opening my mouth, didn't feel like it, etc.) On the days when you did brush write N/A on the line for that day.

Monday _____

Tuesday _____

Wednesday _____

Thursday _____

Friday _____

Saturday _____

Sunday _____

3.On a typical day when you *did* brush your teeth, which of the following did you do? (Please circle **all** that apply to you).

a. I brushed my teeth in the morning
b. I brushed my teeth in the evening before bed
c. I brushed after each meal I ate
d. I brushed after every snack
e. I brushed after some of the meals I ate, but not all
f. I brushed after some of the snacks I had, but not all

4. During the past week, was there ever a day when you completely skipped flossing your teeth? (please circle one answer)

a. no (go to question #6)
b. yes

5. Below you will see a line for each day of the week. On the days that you that you skipped flossing your teeth, please tell us briefly the reason why you did not floss. (Some examples are: forgetting, feeling too tired, did not bring floss, gums too sore, having difficulty opening my mouth, didn't feel like it, etc.) On the days when you did floss write N/A on the line for that day.

Monday _____

Tuesday _____

Wednesday _____

Thursday _____

Friday _____

Saturday _____

Sunday _____

6. On a typical day when you *did* floss your teeth, which of the following did you do? (Please circle all that apply to you).

a. I flossed my teeth in the morning
b. I flossed my teeth in the evening before bed
c. I flossed after each meal I ate
d. I flossed after every snack
e. I flossed after some of the meals I ate, but not all
f. I flossed after some of the snacks I had, but not all

7. During the past week, was there ever a day when you skipped applying fluoride to your teeth? (please circle one answer)

a. no (go to question #9)
b. yes

8. Below you will see a line for each day of the week. On the days that you that you skipped fluoride application, please tell us briefly the reason why you did not apply fluoride. (Some examples are: forgetting, feeling too tired, did not bring fluoride, gums too sore, having difficulty opening my mouth, didn't feel like it, etc.) On the days when you did apply fluoride write N/A on the line for that day.

Monday _____

Tuesday _____

Wednesday _____

Thursday _____

Friday _____

Saturday _____

Sunday _____

9. On a typical day when you applied fluoride to your teeth, how many minutes did you wait before you:

a. rinsed?						
(Circle one answer):	5 min	10 min	15 min	20 min	25 min	30 min
b. ate again?						
(Circle one answer):	5 min	10 min	15 min	20 min	25 min	30 min
c. drank again?						
(Circle one answer):	5 min	10 min	15 min	20 min	25 min	30 min

10. During the past week, was there ever a day when you completely skipped rinsing your mouth with the solution your dentist recommended? (please circle one answer)

a. no (go to question #12)

b. yes

11. Below you will see a line for each day of the week. On the days that you that you skipped rinsing, please tell us briefly the reason why you did not rinse. (Some examples are: forgetting, feeling too tired, did not bring floss, out of rinsing solution, didn't feel like it, etc.) On the days when you did rinse write N/A on the line for that day.

Monday _____

Tuesday _____

Wednesday _____

Thursday _____

Friday _____

Saturday _____

Sunday _____

12. On a typical day when you *did* rinse with the solution that your dentist recommended

which of the following did you do? (Please circle all that apply to you).

g. I rinsed my teeth in the morning
h. I rinsed my teeth in the evening before bed
i. I rinsed after each meal I ate
j. I rinsed after every snack
k. I rinsed after some of the meals I ate, but not all
l. I rinsed after some of the snacks I had, but not all

Cancer Diagnostic Interview Scale (CDIS)

We want to understand how you felt when your dental oncologist told you about your cancer and cancer treatment. Specifically we are interested in how you felt when your dental oncologist spoke to you about the potential for oral complications that you may develop from your radiation therapy.

Please try to recall what you were feeling and thinking, and then indicate the extent to which you agree with each of the following statements. If you saw more than one doctor, please describe the doctor whom you selected to be your dentist.

		Strongly disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly agree
1	**My dentist understood my fears and concerns.**	1	2	3	4	5
2	**I felt hopeful after talking to my dentist.**	1	2	3	4	5
3	**My dentist did not take time to answer all my questions.**	1	2	3	4	5
4	**My dentist was abrupt when he gave me the news.**	1	2	3	4	5
5	**My dentist encouraged me to express my feelings.**	1	2	3	4	5
6	**I was given a lot of information about my cancer and oral health.**	1	2	3	4	5
7	**I believed my dentist would do everything he/she could to maintain my oral health.**	1	2	3	4	5
8	**My dentist discussed different treatments available for the oral complications.**	1	2	3	4	5
9	**I came away from the dentist's office feeling that I was in good hands.**	1	2	3	4	5
10	**My dentist explained the need for tests and procedures.**	1	2	3	4	5

		Strongly disagree	Disagree somewhat	Neutral	Agree somewhat	Strongly agree
11	**I did not understand the information my dentist gave me.**	1	2	3	4	5
12	**My dentist seemed uncomfortable when I became emotional.**	1	2	3	4	5
13	**I wish the dentist had given me more time to ask questions about oral complications and the treatments that are available.**	1	2	3	4	5
14	**I wish that my dentist had been more hopeful.**	1	2	3	4	5
15	**I felt that my dentist cared about me as a person.**	1	2	3	4	5
16	**I got the impression my dentist preferred to remain emotionally detached.**	1	2	3	4	5
17	**My dentist appeared annoyed and impatient with my questions.**	1	2	3	4	5
18	**My dentist is a warm and caring person.**	1	2	3	4	5
19	**My dentist did a good job of explaining the reasons that I might develop oral complications.**	1	2	3	4	5
20	**I was satisfied with the information my dentist provided about the kinds of things I can do to help reduce the oral complications.**	1	2	3	4	5

We are also interested in learning about the kinds of information you were given and who else, beside your dentist may have given you information about your oral care. Please answer the questions below to the best of your ability.

1. In the area of dental oncology, where you saw your dentist, please indicate who of the following individuals gave you information about your oral care and the form of information that was given to (spoken, written, or both). Please circle all that apply. (For example, if a person gave you both spoken and written information circle the number for both those answers.)

		Spoke to me	Gave me written information	Did not give me any information	I don't remember if this person gave me any information
1	**My dentist.**	1	2	3	4
2	**The dental assistant.**	1	2	3	4
3	**The dental hygienist.**	1	2	3	4

2. In the area of radiation oncology, where you saw radiation oncologist and received your radiation treatment, please indicate who of the following individuals gave you information about your oral care and the form of information that was given to (spoken, written, or both). Please circle all that apply. (For example, if a person gave you both spoken and written information circle the number for both those answers.)

		Spoke to me	Gave me written information	Did not give me any information	I don't remember if this person gave me any information
1	**My doctor**	1	2	3	4
2	**The physician assistant.**	1	2	3	4
3	**The nurse.**	1	2	3	4

Adherence Determinants Questionnaire (ADQ)

We are interested in your views about your illness and the recommendations your dental oncologist has made about the oral care program and suggestions that you do not smoke or drink alcohol.

Please indicate the extent to which to agree or disagree with the following statements by circling the answer that best describes how you feel. The phrase "treatment plan" below refers to the recommendations your dental oncologist gave you.

		Strongly disagree	Disagree somewhat	Neither agree nor disagree	Agree somewhat	Strongly agree
1	**The benefits of my treatment plan outweigh any difficulty I might have following it.**	1	2	3	4	5
2	**My treatment plan is too much trouble for what I get out of it.**	1	2	3	4	5
3	**Because my treatment plan is too difficult, it is not worth following.**	1	2	3	4	5
4	**Following my treatment plan is better for me than not following my treatment plan.**	1	2	3	4	5
5	**Following my treatment plan will help me to be healthy.**	1	2	3	4	5
6	**I'll be just as healthy if I avoid my treatment plan.**	1	2	3	4	5
7	**I believe that my treatment plan will help to prevent further oral complications.**	1	2	3	4	5
8	**It's hard to believe that my treatment plan will help me.**	1	2	3	4	5
9	**There are many conditions more severe than the kind of oral complications I am at risk for.**	1	2	3	4	5
10	**The oral complications I am at risk for are not as bad as people say.**	1	2	3	4	5
11	**The kind of oral complications I am at risk for are terrible.**	1	2	3	4	5

		Strongly disagree	Disagree somewhat	Neither agree nor disagree	Agree somewhat	Strongly agree
12	**There is little hope for people with the kind of oral complications I am at risk for.**	1	2	3	4	5
13	**The chances that I might develop oral complications are pretty high.**	1	2	3	4	5
14	**I expect to be oral complications in the future.**	1	2	3	4	5
15	**No matter what I do, there's a good chance of developing Oral complications.**	1	2	3	4	5
16	**My body will fight off oral complications in the future.**	1	2	3	4	5
17	**I have made a commitment to follow my treatment plan.**	1	2	3	4	5
18	**Following my treatment plan is not in my plans.**	1	2	3	4	5
19	**I intend to follow my treatment plan.**	1	2	3	4	5
20	**I have no intentions of following my treatment plan.**	1	2	3	4	5
21	**Lots of things get in the way of following my treatment plan.**	1	2	3	4	5
22	**I need more assistance in order to follow my treatment plan.**	1	2	3	4	5
23	**I get the help I need to carry out my treatment plan.**	1	2	3	4	5
24	**I am able to deal with any problems in following my treatment plan.**	1	2	3	4	5

Illness Perceptions Questionnaire (IPQ) - Causes illness subscale

We are also interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you.

Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by circling the appropriate number.

	POSSIBLE CAUSES	Strongly disagree	Disagree somewhat	Neutral	Agree somewhat	Strongly agree
1	**Stress or worry.**	1	2	3	4	5
2	**Hereditary - it runs in my family.**	1	2	3	4	5
3	**A Germ or virus.**	1	2	3	4	5
4	**Diet or eating habits.**	1	2	3	4	5
5	**Chance or bad luck.**	1	2	3	4	5
6	**Poor medical care in my past.**	1	2	3	4	5
7	**Pollution in the environment.**	1	2	3	4	5
8	**My own behavior.**	1	2	3	4	5
9	**My mental attitude e.g. thinking about life negatively.**	1	2	3	4	5
10	**Family problems or worries caused my illness.**	1	2	3	4	5
11	**Overwork.**	1	2	3	4	5
12	**My emotional state e.g. feeling down, lonely, anxious, empty.**	1	2	3	4	5
13	**Ageing.**	1	2	3	4	5
14	**Alcohol.**	1	2	3	4	5

	POSSIBLE CAUSES	Strongly disagree	Disagree somewhat	Neutral	Agree somewhat	Strongly agree
15	**Tobacco use.**	1	2	3	4	5
16	**Accident or injury.**	1	2	3	4	5
17	**My personality.**	1	2	3	4	5
18	**Altered immunity.**	1	2	3	4	5

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR illness. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

1. _____
2. _____
3. _____

Functional Assessment of Cancer Therapy – Head and Neck (FACT-HN)

Often patients with head and neck cancers will experience physical changes involving the neck and face. These changes may be directly related to the cancer or result from complications associated with cancer treatment. Such physical changes may affect your appearance and/or your ability to perform basic functions involving the mouth and neck.

Below, please indicate to what extent the following statements have been true for you during the last 7 days. Please circle the answer that best describes your experience.

		Not at all	A little bit	Somewhat	Quite a bit	Very much
1	**I am able to eat the foods that I like.**	0	1	2	3	4
2	**My mouth is dry.**	0	1	2	3	4
3	**I have trouble breathing.**	0	1	2	3	4
4	**My voice has is usual quality and strength.**	0	1	2	3	4
5	**I am able to eat as much food as I want.**	0	1	2	3	4
6	**I am unhappy with how my face and neck looks.**	0	1	2	3	4
7	**I can swallow naturally and easily.**	0	1	2	3	4
8	**I am able to communicate with others.**	0	1	2	3	4
9	**I can eat solid foods.**	0	1	2	3	4

10. Do you have a feeding tube?

1. No

2. Yes

3. If yes, when did you get it _____(date)

Brief COPE

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.

Below is a list of responses that people typically use. Please choose your answers carefully by circling the appropriate number. Remember there are no "right" or "wrong" answers so choose the most accurate answer for YOU, that is what YOU do when you experience a stressful event. Please try to answer every item.

		I don't do this at all	I do this a little bit	I do this a medium amount	I do this a lot
1	**I turn to work of other activities to take my mind of things.**	1	2	3	4
2	**I concentrate my efforts on doing something about the situation I'm in.**	1	2	3	4
3	**I say to my self "this isn't real".**	1	2	3	4
4	**I drink alcohol or take other drugs to make myself feel better.**	1	2	3	4
5	**I try to get emotional support from others.**	1	2	3	4
6	**I admit to myself that I cant' deal with it and give up trying.**	1	2	3	4
7	**I take action to try to make the situation better.**	1	2	3	4
8	**I refuse to believe that it has happened.**	1	2	3	4
9	**I say things to let my unpleasant feelings escape.**	1	2	3	4
10	**I use alcohol or other drugs to help me get through it.**	1	2	3	4
11	**I try to see it in a different light, to make it seem more positive.**	1	2	3	4
12	**I try to come up with a strategy about what to do.**	1	2	3	4

13	**I get comfort and understanding from someone.**	1	2	3	4
14	**I give up trying to cope with it.**	1	2	3	4
15	**I to look for something good in what is happening.**	1	2	3	4
16	**I make jokes about it.**	1	2	3	4
17	**I do something to make me think about it less, such as going to the movies, watching TV, reading, daydreaming sleeping, or shopping.**	1	2	3	4
18	**I accept the reality of the fact that it has happened.**	1	2	3	4
19	**I express my negative feelings.**	1	2	3	4
20	**I find comfort in my religion or spiritual beliefs.**	1	2	3	4
21	**I learn to live with it.**	1	2	3	4
22	**I think hard about what steps to take.**	1	2	3	4
23	**I pray or meditate.**	1	2	3	4
24	**I make fun of the situation.**	1	2	3	4

Center for Epidemiologic Studies – Depression Scale (CES-D)

On the line next to each statement, please circle the number of the answer on each line, which best describes how many times during the past week you felt the same way.

	During the past week:	Rarely or none of the time (less than 1 day)	Some or little of the time (1-2 days)	Occasionally or a moderate amount of the time (3-4 days)	Most or all of the time (5-7 days)
1	**I was bothered by things that usually don't bother me.**	0	1	2	3
2	**I did not feel like eating; my appetite was poor.**	0	1	2	3
3	**I felt that I could not shake off the blues even with the help from my family or friends.**	0	1	2	3
4	**I felt that I was just as good as other people.**	0	1	2	3
5	**I had trouble keeping my mind on what I was doing.**	0	1	2	3
6	**I felt depressed.**	0	1	2	3
7	**I felt that everything I did was an effort.**	0	1	2	3
8	**I felt hopeful about the future.**	0	1	2	3
9	**I thought my life had been a failure.**	0	1	2	3
10	**I felt fearful.**	0	1	2	3
11	**My sleep was restless.**	0	1	2	3
12	**I was happy.**	0	1	2	3
13	**I talked less than usual.**	0	1	2	3
14	**I felt lonely.**	0	1	2	3
15	**People were unfriendly.**	0	1	2	3

16	**I enjoyed life.**	0	1	2	3
17	**I had crying spells.**	0	1	2	3
18	**I felt sad.**	0	1	2	3
19	**I felt that people dislike me.**	0	1	2	3
20	**I could not ” get going”.**	0	1	2	3

APPENDIX 2:
Writing Intervention

As mentioned to you earlier we are doing this study to learn more about the kinds of problems patients may encounter in trying to follow their oral care program. We know that the program is very demanding and time consuming. We hope that by learning more about what it is like to try to follow the program during treatment we may be able to help future patients in following their program.

This is your opportunity to tell us it about your personal experience with your dental care program. You have a unique perspective on what it is like to try to carry out a dental care program that is certainly more involved than usual and *can* be very difficult to follow.

Below you will be asked to describe your specific oral care program and provide more information on what it has been like for *you* to follow it. We also ask you to provide us with some feedback about the program and suggestions for how to improve it.

When answering the questions, please take some time to really *think about* and *reflect on* your experience, your insight and experience is very valuable to us!

1. Please describe your dental care program as your doctor has explained it to you.

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2. How do you feel about following the program so far? For example, has it been difficult or easy? Do you find it bothersome or annoying? Or do you feel good about doing it?

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3. Which parts of the program have been the easiest to do? And why?

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4. Which parts of the program have been the most difficult to do? And why?

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5. Have you come up with any strategies, or plans, that have helped you in following the program, and, if so, what are they?

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6. Are there things you wish that your doctor or the hospital could have done for you? (Remember all your feedback will remain confidential and your doctor will not learn of your answer to these questions)

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7. Do you have any ideas for how we can better help persons like yourself in the future?

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8. Do you have any other comments or things you think we should know about the oral care program and your particular experience?

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Thank you so much for your time and input!

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